



# ZERO TO THREE<sup>®</sup>

March 2011 Volume 31 No. 4

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*Journal of ZERO TO THREE: National Center for Infants, Toddlers, and Families*

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## Children With Special Needs

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Top 10 Mistakes in Early  
Intervention

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Features of High-Quality Inclusion

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Sustaining Family Involvement

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Federal Policy Opportunities

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**Also in This Issue:**

Lessons Learned From the Early Childhood  
Assessment Workshop

## THIS ISSUE AND WHY IT MATTERS

This year marks the 25th anniversary of the passage of Public Law 99-457, the Education of the Handicapped Act Amendments of 1986. Ronald Reagan signed the bill into law at a time when the United States was facing a severe economic downturn. Despite repeated challenges for funding, the program continues to this day. Many of the children who “graduated” from early intervention 25 years ago have completed their education, entered the workforce, and are contributing to their communities. Their parents and caregivers were pioneers in leading and improving early intervention services and today are helping new parents navigate and lead the system. This is the success of early intervention.

Creating the comprehensive, coordinated system envisioned in Public Law 99-457 is a formidable task. The “glue money” provided by the federal government barely covers the cost of implementing a system that meets the required elements of being “comprehensive,” “multidisciplinary,” and “interagency.” The individuals who take on this task, and the families that guide them, are heroes. They are also weary, a bit discouraged, and frustrated by the lack of action to reauthorize Part C with adequate and sustainable funding. Still, they push for progress.

There is more to be done. The articles in this issue of the *Zero To Three* Journal bring attention to current issues in Part C early intervention, highlight innovative community efforts, consider ways to benefit from parent leadership, and outline strategies to renew the early intervention field’s commitment to quality. These articles describe the evolution of state early intervention systems and the issues they continue to face: financing, personnel, improving quality and compliance issues. The intent and spirit of early intervention can be realized only if these issues are promptly addressed at federal and state levels.

A new vision—or perhaps a return to the original vision—of effective early intervention is described both in principle and in practice. Details about an outreach and screening project in the San Fernando Valley in California illustrate how building relationships and respecting culture, language, and traditions of parents as well as of providers can fully engage a community in supporting all its families and children. The features of high-quality inclusion are defined and reinforced by a national consensus statement and a solid base of evidence. Parallel requirements between Early Head Start and early intervention provide an opportunity to create meaningful partnerships for families living in poverty. Respect for family involvement is a keystone of early intervention; the article by the members of Early Intervention Family Alliance highlights the role of parents as leaders and change agents in early intervention systems. Authors also examine opportunities in federal and state policy to strengthen early intervention services and supports and to more fully integrate with broader early learning, health, mental health, and family agendas.

Early experiences matter, and they matter for *all* children. In this 25th year of early intervention, we must look closely at where we’ve been and where we want to go. I hope that the information and perspectives offered in this journal renew our commitment to early intervention, build on the strengths of families as partners and leaders, and provide us with clear direction for improving services and policies.

Cindy Oser, Guest Editor  
Senior Policy Analyst, ZERO TO THREE Policy Center  
coser@zerotothree.org



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# From Then to Now

## *The Evolution of Part C*

**KATHLEEN HEBBELER**

*SRI International  
Menlo Park, California*

**MAUREEN GREER**

*IDEA Infant and Toddler Coordinators Association  
Indianapolis, Indiana*

**BRADLEY HUTTON**

*New York State Department of Health's Bureau of Early Intervention  
Albany, New York*

In 1986, Congress made a significant change to the federal legislation governing special educational services for children with disabilities. The law was amended to create a new program addressing services for children less than 3 years old with developmental delays and disabilities and their families. This program continues today as Part C, Infants and Toddlers With Disabilities, of the federal Individuals With Disabilities Education Act (IDEA, 2004). Part C provides grants to states “to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families” (Sec. 631(b)(1)). Part C of IDEA remains an optional program for states, but if a state chooses to apply for Part C funds (and all states and six jurisdictions<sup>1</sup> currently do) then the state must comply with all of the provisions of the law including identifying a lead agency and providing services to all eligible infants and toddlers and their families.

Unlike the IDEA programs for children 3-21 years old, one of the stated purposes of Part C is to build the capacity of families to meet the special needs of their child. The law's emphasis on family is reflected in the Individualized Family Service Plan (IFSP), a service plan which is to be developed for each participating family and documents both the child and family outcomes to be addressed and the services that will be provided. Part C was envisioned as a partnership between parents and professionals with family resources, concerns, and

priorities being central to decisions related to outcomes and services (Beckman, Robinson, Rosenberg, & Filer, 1994).

Making the Part C vision of family-centered service and supports a reality for children and families required changes at both the state and local levels. Although a few states were providing services to some segments of this population in 1986, no state had all of the program components required by the law (Meisels, Harbin, Modigliani, & Olson, 1988). States had to put in place a state-level infrastructure that included designating a lead agency to monitor and support implementation, establishing an Interagency Coordinating Council, and instituting

mechanisms for helping the public learn about early intervention services. States also had to address issues of personnel qualifications and preparation and build a service delivery system at the local level. By 1994, all states had made progress in developing their comprehensive systems and in creating mechanisms to coordinate and facilitate planning and were “looking into complexities

### **Abstract**

**The implementation of Part C of IDEA has continued to evolve as states have built and modified service delivery systems. The number of children served has increased dramatically with nearly 350,000 children and their families now receiving early intervention services. Meanwhile, challenges to the provision of quality services—such as securing adequate funding, staffing programs with qualified personnel, and monitoring for quality—persist. A new development for Part C is the systematic collection of data on child outcomes. The upcoming reauthorization of IDEA presents an opportunity to further refine this important federal program for children less than 3 years old and their families.**

<sup>1</sup> Throughout this article, the word “state” will be used to refer to the 50 states and 6 jurisdictions participating in Part C.

of ensuring that personnel are qualified” (Trohanis, 1994, p. 218). States adopted different structures for providing early intervention services that included the use of public and private programs and providers to varying degrees (Spiker, Hebbeler, Wagner, Cameto, & McKenna, 2000).

In the nearly 25 years since Part C was created, the implementation of the program has continued to evolve in response to multiple factors. The number of children and families served has increased and the knowledge base regarding effective services continues to expand. Meanwhile, chronic challenges such as shortages of appropriately trained personnel and insufficient funding persist. This article discusses five areas related to Part C implementation to illustrate some critical issues and new developments that are influencing how early intervention services are being provided around the country.

## Who Is Served

**I**MPLEMENTATION OF PART C has often been characterized by variation across states, especially because the law gives states discretion in establishing eligibility criteria. The law requires that each state must serve children with either a developmental delay in one or more of five domains, (cognitive, physical, communication, social or emotional, and adaptive), or a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. In addition, states may elect to serve infants who are at-risk for developmental delay as a result of biological or environmental risk factors or children who are eligible for preschool special education services who have been served by the Part C system and whose parents wish to stay in the Part C system. The number of states including children at-risk in the population eligible for early intervention has varied over the years but has always been small. In 2010, there were seven states (American Samoa, Guam, Illinois, Massachusetts, New Hampshire, New Mexico, and West Virginia; Ringwalt, in press) serving children at risk through the Part C program.

States are required to establish eligibility criteria for developmental delay using a metric such as percentage delay, standard deviation, or delay in months. Many states use some combination of methods that most often includes the use of a percentage delay (Shackelford, 2006). The percentage of delay varies across states from “any delay” in a developmental domain to a 50% delay in one developmental domain. Over the past 8 years, as a result of the fiscal challenges faced by state Part C systems, an increasing number of states have narrowed their eligibility criteria, requiring a higher percentage of delay for eligibility. In addition, some states have



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**Part C is designed to build the capacity of families to meet the special needs of their child.**

begun moving away from the use of percentage delays because they can result in misuse of age equivalent scores from assessment tools. A 2009 survey of Part C coordinators found that seven states had narrowed eligibility, nine were considering narrowing eligibility, one had expanded eligibility, and two were considering expanding eligibility (IDEA Infants and Toddlers Coordinators Association [ITCA], 2009).

One of the strongest indicators of how much change has occurred in the Part C program since its creation is the dramatic increase in the number of children receiving services. At the end of 1992, 143,000 children and families were reported to be receiving early intervention through Part C. By 2009, the number had more than doubled to 349,000. As a percentage of the general population less than 3 years old, the growth has been from 1.18% to 2.67% (U.S. Department of Education, 2009). Given that each state establishes its own eligibility criteria for Part C within the parameters of the federal law, there has always been considerable variation in the percentage of children served across states. The percentage of the general population served in the fall of 2009 varied across states from 1.24% in Georgia to 6.5% in Massachusetts (U.S. Department of Education).

The national data available from the U.S. Department of Education on the numbers and percentage of children served evokes differing responses from the early childhood research community. Some researchers have written that Part C systems are leaving many potentially eligible children without services (Rosenberg, Zhang, & Robinson,

2008), and other researchers believe that the methodology used by the federal government for counting children underestimates states' efforts (Dunst, Fromewick, & Hamby, 2004). Currently, the U.S. Department of Education collects two types of data: a mandatory single-day count of children enrolled in Part C and the optional yearly aggregate number of children served. An alternative measure is the proportion of children born in a given year who were ever served in the state's Part C program. In an attempt to examine this issue, the ITCA has begun a birth cohort study to track children born in 2006 who may have been referred, evaluated, or enrolled in a Part C system at any point during their 3-year period of potential eligibility. Data from this study suggest that the number of children who have contact with the Part C system is a least 3 times as high as the single-day count. The use of a birth cohort measure and including children who are referred along with those who are ultimately served more accurately represents the scope of the Part C program's reach within the population of infants and toddlers nationally.

## Financing the Part C System

**P**ART C was developed as a new kind of entitlement system. Each year, an authorized official from each state must reaffirm that state's commitment to participate and provide assurances of its compliance with federal requirements. In addition, unlike other entitlement programs that have dedicated federal funding for required services, Congress charged state Part C systems with coordinating multiple



**Each state receives a federal Part C grant based on the number of infants and toddlers in the general population in the state.**

federal and state funding sources to support the infrastructure and service needs of eligible children. The federal Part C funding allocated to states and jurisdictions was designed to be “glue money,” funding that would support interagency infrastructure activities and would be used for direct services only when all other resources had been exhausted. The federal regulations for Part C identify five federal programs as resources to support the Part C system: Title V of the Social Security Act of 1935 (Maternal and Child Health); Title XIX of the Social Security Act of 1965 (Medicaid and EPSDT); the Head Start Act (1998); IDEA (2004); and the Developmental Disabilities Assistance and Bill of Rights (1975).

Each state receives a federal Part C grant that is based on the number of infants and toddlers in the general population in the state, not on the actual number of children served in the program. The federal Part C allocation increased dramatically between 1992 and 2004, from \$175 million to \$444 million, but since 2004, funding has been essentially flat with the exception of one-time American Recovery and Reinvestment Act of 2009 (ARRA) funding. The increase in the number of children served has resulted in a significant decrease in the federal Part C per-child allocation from a high of \$1,975 in 1999 to \$1,283 in 2009 (excluding the one-time 2009 ARRA funds; National Early Childhood Technical Assistance Center, 2010).

Each state has developed a unique system of financing that builds on federal, state, and local funding sources. Although there are sources of funding in common across states,

the type and amount of state and local funds varies dramatically. State Part C coordinators from 40 states and jurisdictions reported to ITCA that more than \$3 billion dollars was financing Part C systems. Most (55%) funds come from the state level, with 31% from federal funds, and 14% from local fund sources. The state coordinators reported that federal Part C funds account for less than 12% of the total funds supporting early intervention systems. All 40 states could identify the fund sources that were being used, but only 15 states were able to identify the total dollar amount of each of the fund sources. The median number of fund sources used by states across all three levels was five (IDEA Infants and Toddlers Coordinators Association, 2010a).

Navigating the complex array of financing options remains challenging for states. Sources of Medicaid financing vary greatly among states including use of Medicaid coverage under Early Periodic Screening Detection and Treatment (EPSDT), the rehabilitative coverage option, targeted case management, and section 1915 home and community-based waivers. Although most states access Medicaid coverage to support their Part C program, the other sources identified in federal regulations are used less often. Only 13 states reported they used funds from the Maternal and Child Health Block grant, 2 states used Early Head Start funds, and 6 states used the Developmental Disabilities Block grant.

The sharp decline in federal Part C funds per child has placed increasing pressure on states to expand the level of support from

other sources or lower costs through, for example, narrowing eligibility or implementing fees for families. Some states have even considered withdrawing from the federal Part C program in part as a result of financial and other program pressures. In 2009, seven states were having high-level discussions about withdrawing from Part C, although this declined to one state in the 2010 (IDEA Infants and Toddlers Coordinators Association, 2009, 2010a). This reprieve is likely temporary due to additional ARRA Part C funding in 2009.

Wide variation in sources and amounts of financing across states has also contributed to an unequal implementation of the program across the country. Variation in the percentages of children enrolled by state is one obvious manifestation of this. Another is the variation in the level of services provided to enrolled children. In 2010, states reported the average number of hours of service provided per month per child amount ranged from 2 hours per month to 30 hours per month. Equally interesting was that more than half (26 out of 50) of the states responding to the survey did not have data on how much service children were receiving (IDEA Infants and Toddlers Coordinators Association, 2010b). The desirability and impact on children and families of such extreme state-to-state variation in a national program remains an important issue. In addition, more information is needed on the delivery of Part C services, including the amount of service provided, and more research is needed to examine the cost-effectiveness of the diverse array of service delivery options in Part C systems.

Adequate financing for early intervention services has been a persistent problem since Part C was created. The current dire economic situation has turned this problem into a crisis in many states. The Congressional assumption that early intervention services could be adequately supported by coordinating existing funding sources was erroneous and stands in stark contrast to the fiscal reality that state Part C programs face in 2011. The upcoming reauthorization of IDEA will provide an important opportunity for policymakers to revisit how Part C can be funded so states are not forced to serve fewer children or provide less service.

## Personnel

**A**N ADEQUATE SUPPLY of qualified personnel has been recognized as essential to providing effective services for children and families since the creation of the Part C program (Bailey, 1989; Klein & Gilkerson, 2000; Lucas, Hurth, & Kasprzak, 2010). No national data are available on how many professionals are providing early intervention services across

the country. Although IDEA lists 16 different early intervention services, most families receive one or more of a small common core of services. Nearly all families receive services from at least one professional from the disciplines of early intervention, speech and language therapy, physical therapy, or occupational therapy (Hebbeler, Spiker, Morrison, & Mallik, 2008). In addition, families will be receiving service coordination, which must be offered to all families and may be provided by professionals from different disciplines (Bruder, 2005). Because they provide the overwhelming majority of early intervention services, an adequate pool of personnel in the common core disciplines is essential to the provision of quality early intervention services.

Workforce issues continue to present myriad challenges to the provision of high-quality early intervention services 25 years after the law's passage. Personnel challenges do not arise from a single source and thus do not have a single solution. Some of the interrelated factors contributing to both the supply and demand for qualified personnel include credential and licensing requirements, service delivery models for providing early intervention and their associated staffing patterns, the availability of programs in institutions of higher education for training the next generation of providers, the influence of professional associations that represent the interest of the various disciplines providing early intervention and establish national standards, federal support for programs that provide pre-service and in-service training for professionals, and funding levels for early intervention services (Hebbeler, 1997).

Part C requires that states establish qualifications for early intervention personnel. High standards are needed for quality service provision but also create personnel shortages by restricting the pool of potential providers. Another area of variation across states for Part C is the requirements for early intervention personnel. For example, 73% of states require a bachelor's degree for early interventionists, 27% require a master's degree, and 7% require a certificate from a professional association. The corresponding numbers for service coordinators are 71%, 20%, and 5%. These figures contrast with the requirements for speech language pathologists for whom 63% of states require a master's degree, 10% require a bachelor's degree, and 37% require certification from a professional association (Sopko, 2010).

Nearly all states report shortages of early intervention personnel with the most severe shortages being in professions providing the common core of services reported above:

## Personnel challenges do not arise from a single source and thus do not have a single solution.

speech language pathologists (81% of states reporting a shortage), physical therapists (74%), occupational therapists (54%), and early interventionists (31%; Sopko, 2010). States identify a variety of barriers to obtaining adequate numbers of personnel including an inadequate supply; insufficient salary and benefits, especially when early intervention programs compete with school districts, the private sector, and hospitals, who are potential employers for the same pool of professionals; and factors related to geography, such as finding personnel in rural areas or who are willing to drive long distances or face the safety issues of working in some urban areas. Other personnel challenges for states are inconsistent funding, the need for bilingual personnel, staff turnover, and oversight of personnel (A.J. Papanikou Center for Excellence in Developmental Disabilities, 2006; Sopko, 2010).

Higher education plays a critical role in addressing the problem of personnel shortages through both pre-service and in-service training. Yet in one survey, only 25 out of 41 states reported coordinating with institutions of higher education (Sopko, 2010). In another survey, 58% of states reported having higher education programs specific to early intervention professional preparation, and 62% reported having additional agencies that provide early intervention training. Inadequacies in the content of preparation programs for therapists has been an ongoing problem especially with regard to areas critical to early intervention such service coordination or teaming (Bailey, Simeonsson, Yoder, & Huntington, 1990; Bruder & Dunst, 2005). It is not surprising that a lack of adequate preparation creates a problem for service provision. States reported a need for additional early intervention training for speech therapists (24% of states), physical therapists (24%), and occupational therapists (22%; A.J. Papanikou Center for Excellence in Developmental Disabilities, 2006).

The persistent and daunting challenges related to personnel must be addressed if the vision of the law is to be realized. Despite the many issues related to training, hiring, and retaining a qualified work force in Part C, dedicated early intervention professionals sit down every week with families to help

them support the development of their child. As Congress moves forward with reauthorization of IDEA and the next evolution of Part C, it will be important to find ways to support these providers in what they do and to continue to build the infrastructure to develop the next generation of professionals who will follow in their footsteps.

## Efforts to Ensure Quality and Compliance

**E**NSURING THAT EVERY early intervention program provides high quality early intervention service is not an easy undertaking. IDEA requires the state agency to monitor how local programs provide services and the U.S. Department of Education to monitor state implementation. The provision of Part C services is governed by federal law, but many of the law's requirements address aspects of service delivery such as timelines and required signatures that are not directly linked to effectiveness of intervention. Early intervention services must comply with legal requirements but, to be effective, services also need to reflect the current research and recommend practices (Sandall, Hemmeter, McLean, & Smith, 2004). An ongoing struggle for the administration of Part C has been how to design a monitoring system that supports states and local programs in providing services that are effective as well as in compliance with the law.

The 2004 reauthorization of IDEA included a new approach for examining each state's implementation of the law's requirements. States were required to develop a State Performance Plan (SPP) and to report on progress through an Annual Performance Report (APR). The 2004 reauthorization identified four priority indicator areas for Part C including child find, natural environments, transition, and general supervision. State Part C agencies now report on progress toward targets for 14 required indicators (the indicators for Part C can be found at [www2.ed.gov/policy/speced/guid/idea/capr/2010/b2-1820-0578cmeatable111210.pdf](http://www2.ed.gov/policy/speced/guid/idea/capr/2010/b2-1820-0578cmeatable111210.pdf)) in the APR. The Office of Special Education Programs (OSEP) in the U.S. Department of Education reviews each state's APR annually and determines each state's compliance with the requirements of Part C of IDEA. On the basis of the information provided by the state, OSEP determines whether the state meets requirements, needs assistance, needs intervention, or needs substantial intervention. Over time, OSEP has found that a growing percentage of states meet the requirements under IDEA Part C, increasing from 27% in 2005 to 50% in 2008.

This increase in the number of states found to meet requirements would seem to



*the increasing administrative and statutory requirements of Part C. These increased requirements create an enormous burden on states and territories who are struggling to identify sufficient resources to support the administrative and direct service requirements of the system (ITCA, 2007, p. 2)*

The federal role in monitoring state compliance with the requirements of IDEA is essential for ensuring that children and families receive all the rights afforded to them under Part C. However, the oversight of Part C would benefit from effective efforts to improve the quality of services along with monitoring for compliance. In addition, many states feel the burden of maintaining and demonstrating compliance with Part C of IDEA has too often distracted states from efforts to maintain or increase the number of children served and to improve the quality of services received. The performance measurement system for Part C could be improved through a more meaningful set of indicators that incorporates metrics of the quality of the services provided to children and families as well as the state's compliance with the law's requirements.

### Measuring Outcomes for Children and Families

PRIOR TO THE passage of the Education for All Handicapped Children Act of 1975, the original legislation that is now IDEA, children and youth with disabilities were being denied an education in public schools. Much of the policy focus in the decades that followed, including the amendment that added Part C in 1986, addressed getting children with disabilities access to needed services. In the early 1990s, research on adolescents who had received special education revealed that far too many of these young people had poor outcomes. They were not finding jobs, they were not attending postsecondary schools, nor were they able to live independently (Wagner et al., 1991). This research contributed to an important shift in focus in the special education community from making sure children had access to services to ensuring they were achieving good outcomes. As noted in the previous section, the President's Commission on Excellence in Special Education (2002) also emphasized the importance of examining the results being achieved under IDEA.

At the same time, in both the public and private sectors, there was a push for greater accountability and for the collection of information on the intended outcomes of programs (Osbourne & Gaebler, 1992). At the federal level, this movement was reflected in the Government Performance and Results Act (1993) which requires all federal programs to

### Higher education plays a critical role in addressing the problem of personnel shortages through both pre-service and in-service training.

indicate improved programs and services delivered to children in Part C programs nationally, but the determinations are based solely on the 14 SPP/APR indicators which assess only a narrow slice of program performance. OSEP has designated 7 of the 14 indicators as "compliance" indicators which means that state performance on the indicator must be at 100%. Some would argue that evaluating state implementation on a set of narrow indicators has led to states expending substantial resources to produce better numbers that do not actually reflect improved

services. As one brief example, one of the compliance indicators addresses the percentage of infants and toddlers with IFSPs who receive services in a timely manner. OSEP allows states to establish their own definitions of what constitutes receiving services in a timely manner. Between 2005 and 2008, some states relaxed the number of days in their criteria for timely service, making it easier for them to meet the criteria. Efforts to secure increased performance on the APR indicators coupled with the inadequate standardization of the data collection and reporting requirements has resulted in states finding ways to show improved performance on the indicators which may have, ironically, compromised the quality of services to infants and toddlers served under Part C.

The inclusion of performance indicators in the 2004 reauthorization of IDEA grew in part out of concern that the U.S. Department of Education had focused "its monitoring efforts too much on process compliance and has paid little to no attention to monitoring for results" (President's Commission on Excellence in Special Education, 2002). Unfortunately, states continue to be concerned that the direction reflected in the SPP/APR is overly focused on compliance to the detriment of quality services. Comments submitted by ITCA in response to the 2007 Notice of Proposed Rulemaking for Part C which proposed new compliance requirements reflect these concerns:

*ITCA supports changes that will positively impact young children and their families. States and territories face challenges to meet*

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annually report on program outcomes. The only national outcome data on Part C was from the National Early Longitudinal Study. The study found good outcomes for children who had participated in Part C, however, it followed only one group of 3,338 children from early intervention through kindergarten (Hebbeler et al., 2007). Government Performance and Results Act indicators were to be reported on annually so that outcomes could be tracked over time. The lack of outcome data for children and families participating in Part C became especially problematic in 2003 when the Office of Management and Budget instituted a new budgetary review process with the intent of ensuring that funding decisions were based on demonstrated effectiveness. Lacking data on outcomes, Part C was given a score of 0 for accountability and labeled as “Results Not Demonstrated” (Hebbeler, Barton, & Mallik, 2008).

The widespread recognition of the need to have information addressing whether or not programs are achieving their intended outcomes has resulted in a federal requirement for the collection and reporting of data on child outcomes for Part C. The U.S. Department of Education developed an APR indicator on progress toward three child outcomes: social relationships, the acquisition and use of knowledge and skills, and taking action to meet needs. An extensive stakeholder process that included state and local administrators, families, researchers, policymakers, professional associations, advocates, and others was used to identify three child and five family outcomes for which Part C program should be held accountable (Bailey et al., 2006; Hebbeler & Barton, 2007). States are required to annually publish data on child outcomes for the state and, beginning in 2011, by local program as well. Over the last several years, states have undertaken extensive efforts to build measurement systems to collect data on child outcomes. States have adopted a variety of approaches and are in various stages in 2011 with regard to their capacity to produce valid and reliable statewide data. Each year the quality of the data submitted by states continues to improve, indicating that, in the not too distant

future, national data on the outcomes achieved by children in Part C will be available annually. More information about the child and family outcomes, the reporting requirements, and state approaches can be obtained at [www.the-eco-center.org](http://www.the-eco-center.org).


Even though the impetus for the collection of child outcomes data came from the federal government, many state and local programs have welcomed the collection of data on child and family outcomes. In these times of tight budgets, many within and outside of the Part C system recognize the importance of looking at the overall effectiveness of programs. There is much to be learned from programs that are achieving good outcomes and, conversely, programs that are less successful need to be provided support so they too can help children and families achieve good outcomes. It can be hoped that the regular collection and use of data on child outcomes will become a powerful tool for program improvement in the coming years.

## Moving Forward

**T**HE POTENTIAL OF early intervention services to make a meaningful difference in the lives of infants and toddlers experiencing delays and disabilities, and in the lives of their families, is as real today as it was when the law was passed. The initial wave of excitement about the incredible potential of the Part C program has been somewhat tempered by the many and significant challenges states have encountered in trying to build the infrastructure to support the delivery of quality services. There have been many successes—a major one being that on any given day nearly 350,000 children and their families are receiving early intervention services with all of the rights and protections afforded them under the law. States continue to struggle with how to pay for services and how to ensure that each family is receiving effective services from qualified personnel. More data are being collected and reported than ever before, but there is still much we do not know about cost-effective service delivery. None of this is surprising for an enterprise as complex as building a national system of high

quality early intervention services. In 1989, Ed Martin, a former federal official charged with the implementation of the original law that later became IDEA, reflected on the passage of Part C. His words are as profound today as they were then:

*I think it would be unrealistic to assume that the new programs for ... youngsters from birth to 2 years will soon achieve high-quality service success ... On the contrary, I think what we have to expect is that we have achieved a kind of victory in principle with the passage of the act and that we now begin a long, frustrating process of evolution toward the kinds of quality programs that are necessary.” (1989, p. 31).*

Evolution is a long, slow process but for the sake of the children and families who will turn to early intervention in the coming years, the early intervention community needs to continue to steadfastly address the challenges posed by Part C implementation and move quickly to close the gap between vision and reality. 

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**KATHLEEN HEBBELER**, is a program manager at SRI International. She directs the Early Childhood Outcomes (ECO) Center, a 10-year project that provides national leadership around issues related to the development of state-level outcomes measurement systems for programs serving young children with disabilities and their families.

**MAUREEN H. GREER** is the current executive director and past president of the IDEA Infant and Toddler Coordinators Association. Ms. Greer is also the principal of Emerald Consulting, specializing in perinatal and early childhood policy, evaluation, data, and finance. Prior to establishing Emerald Consulting, Maureen spent 8 years as the Part C Coordinator in Indiana.

**BRADLEY HUTTON, MPH**, is the director of the New York State Department of Health’s Bureau of Early Intervention where he has served as the Part C Coordinator for the last 4 years. He served as the president of the IDEA Infant and Toddler Coordinators Association in 2010.

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# The Top 10 Mistakes in Early Intervention in Natural Environments—and the Solutions

R. A. McWILLIAM

*Siskin Children's Institute  
Chattanooga, Tennessee*

**E**arly intervention for children with disabilities is now commonplace, but bad habits have crept in. In this article I describe the top 10 mistakes early intervention providers make, and I offer some solutions. *Early intervention* here refers to the services operated under Part C of the Individuals With Disabilities Education Improvement Act (Public Law 108-446, 118 Stat. 2647); Part C refers to infants and toddlers with disabilities and their families. Sometimes, early intervention is used to refer to a broader range, such as children from disadvantaged backgrounds. Although I specifically refer to Part C, some of the mistakes and solutions indeed apply to the wider field of early childhood education.

Part C services are (a) multidisciplinary and multiagency and (b) family-centered. The first characteristic means that professionals from many different disciplines, such as early childhood special education, early childhood education, speech-language pathology, occupational therapy, and physical therapy, work in early intervention. Furthermore, these professionals might come from early intervention programs, health departments, home health agencies, rehabilitation departments in hospitals, and so on. The second characteristic should mean that professionals treat families in family-friendly ways, which, by and large, they do, and also attend to family-level (e.g., adult) needs, which, by and large, they don't (Turnbull et al., 2007).

Early intervention has been around for about 35 years but was only codified by

law in 1986, with the passage of Public Law 99-457; Education of the Handicapped Act Amendments of 1986). Since then, early intervention professionals have seen changes that have not advanced the field nor served children and families well. A fee-for-service method of paying for early intervention has led to purveyors of services scrambling madly for this new business. Because many of these service providers came from the medical model (actually, better tagged the "rehab" model), they established services in clinics instead of homes, they worked directly with children instead of their caregivers, and they were equally concerned with how to pay for services as with how well the child and family did. These kinds of changes have led to early intervention looking like John McKnight's (1996) "careless society," in which the roles of families and other natural caregivers are usurped by professionals. This change was forewarned as early as 1985 (one year before the law was

even passed) by Carl Dunst (1985), a pioneer in family-centered approaches to early intervention. Recently, we have heard calls to return to the conceptual roots of early intervention. The National Early Childhood Technical Assistance Center at the Frank Porter Graham Child Development Institute, which is at the University of North Carolina at Chapel Hill, convened a work group including nationally recognized early intervention experts (Workgroup on Principles and Practices in Natural Environments, 2007). This group asserted that the mission of early intervention was as follows: "Part C early

## Abstract

**Early intervention for infants and toddlers with disabilities and their families has strayed from its conceptual roots and the intent of the original legislation. The author describes the top 10 mistakes commonly made in early intervention, including what happens at intake, assessment, plan development, and delivery of services. He proposes five practices as a natural-environments approach to fixing these mistakes. The essence of this alternative approach is to recognize natural caregivers, such as parents and child care providers, as intervention agents and to ensure children are getting valid interventions.**

*Note: This article was developed from an invited presentation made at the International Division for Early Childhood Conference, Minneapolis, MN, October 2008.*



### Part C services are family-centered.

intervention builds upon and provides supports and resources to assist family members and caregivers to enhance children's learning and development through everyday learning opportunities" (p. 2). The seven principles they also agreed upon elaborate on the key pieces of this mission: supports are more than services, and assistance goes to adults, who help children in everyday routines—not in set-aside, specialized times and places. Those routines can be in homes, child care, or early-childhood classrooms.

Changes in the field and the recent appeal to go back to the original intent of early intervention provide the backdrop to the top 10 mistakes being made in early intervention.

## The Top 10

**T**HE MISTAKES LISTED here are my personal irritations, gleaned from spending hours with practitioners and directors across the U.S.

### 1. DOING ALL THE TALKING AT INTAKE VISITS

Intake visits are the first visits by early intervention personnel to a family. The professionals have much to do at these visits: describe the program, get financial information, find out about medical concerns, determine whether the child has an established condition, determine whether the child will need to be tested for eligibility, ask the family for consent to evaluate, and so on. These questions are all quite bureaucratic, meaning that they are largely for the benefit of the agency—to get paperwork completed so the family can participate in the program.

### 2. ASKING FAMILIES ABOUT DAILY ROUTINES AT EVERY MEETING LEADING UP TO PLAN DEVELOPMENT

Early interventionists have known for a long time that capturing information about what a child does in a typical day might give some insight to functional needs for intervention, so they have asked about daily routines, at one level or another, at intake, at the evaluation, and sometimes even at the individualized family service plan (IFSP) meeting.

Families hate having to repeat information. Apart from being tiresome, it makes them feel that professionals, at best, aren't communicating or, at worst, aren't listening.

### 3. BASING GOALS ONLY ON WHAT PARENTS SAY THEY WANT

In their desire to be family-centered, professionals often ask parents what their main concerns are so these concerns can be turned into outcomes (i.e., goals) on the IFSP. This well-meaning question is usually asked after a child has been tested and found to be eligible on the basis of delay or after the program has documentation that the child has an established condition.

When parents answer this question, they have little basis for giving a well-thought-out answer, so they either try to deflect the question back to the professionals (e.g., "What do you think I should be concerned about?") or they mention the most obvious areas of infant or toddler development: talking and walking—or the steps leading up to talking and walking. That's why IFSPs on average have fewer than three outcomes, therefore missing many other functional needs the child might have and, just as important, the needs of the parents related to the child's development and learning. Many IFSPs are still shockingly child-oriented instead of family-oriented (Jung & McWilliam, 2005).

### 4. IGNORING THE PARTICIPATION PURPOSE OF CHILD-LEVEL GOALS AND SKIMPING ON MEASURABILITY OF GOALS

Why do early interventionists address deficits in child functioning? They sometimes lose sight of the purpose of intervention. The child's acquisition of a skill isn't an end in itself; it's a means to participation in home, "school," and community. To ensure early interventionists really improve functioning, therefore, it's imperative that they keep the purpose of the behavior at the forefront of the intervention. Otherwise, they might teach the child the skill without applying it to a functional context, rendering it a pretty useless skill. The second part of this mistake refers to the fact that many IFSP outcomes are not clearly measurable: It's hard to tell how one judges progress or whether the outcome (think goal) has been attained.

### 5. MATCHING SERVICES TO DEFICITS

In many communities, services are decided on the basis of the child's diagnosis or what he cannot do. Because this decision is not based on the support that people already working with the child actually need, it leads to a pile-on of services that (a) overwhelms natural caregivers, (b) often produces a fragmented intervention plan, and (c) is very costly, thus reducing the opportunity to meet unmet needs such as families who need more visits, children who need child care subsidized, and so on.

### 6. WORKING DIRECTLY WITH THE CHILD ON HOME VISITS

The most common setting for early intervention services is the home, and most home visitors have adopted a clinic-based approach and dumped it on the living room floor. That is, they spend most of their time working directly with the child (Peterson, Luze, Eshbaugh, Jeon, & Kantz, 2007).

This approach means the child essentially receives intervention only when the home visitor is there, whereas, if the home visitor were to work with the parents, the child could receive intervention when the home visitor isn't there, which of course is much more of the time. Therefore, direct, hands-on work with the child during a home visit is actually underserving a child and family.

### 7. MODELING OR DEMONSTRATING BLINDLY

Early interventionists sometimes delude themselves into believing they're working with children to demonstrate techniques for families in the home or teachers in the classroom. If they simply interact with the child, without letting the caregiver know they're modeling a technique, however, it is unlikely the caregiver will pay attention to the early interventionist's purported demonstration. That means it's unlikely they will imitate the demonstration later, when the early interventionist isn't there.

This can be considered the model and pray approach: You model and pray that the caregiver will imitate. It is a mistake because it wastes the opportunity to demonstrate effectively and, simultaneously, might lead the caregiver to the erroneous conclusion that the hands-on work was real intervention.

### 8. USING THE SAME HOME VISITING APPROACH FOR ALL FAMILIES

Home visitors who go into home after home with toy bags, working with children, are missing the opportunity to meet actual needs in the family. If they have good, functional IFSPs, they have meaningful topics to discuss with families. A support-based, responsive approach to home visiting means

that addressing those topics will result in very different kinds of home visits (McWilliam & Scott, 2001).

## 9. FOCUSING EXCLUSIVELY ON THE CHILD'S WELL-BEING AND QUALITY OF LIFE

Family systems theory makes it clear that the well-being of one member of the family affects the well-being of other members of the family (Bronfenbrenner, 1986). To be effective in early intervention, therefore, early interventionists need to attend to the emotional, material, and informational support needs of the parents (Guralnick, 2007).

## 10. WORKING ONLY WITH CHILDREN IN CLASSROOMS

For a similar reason that working directly with children on home visits is a mistake, when early interventionists visit children in group care, they sometimes take the child to the side of the classroom and work with the child on predetermined skills. This work is not related to the ongoing classroom routines, so the teachers pay little attention—which they might as well do, considering the early intervention isn't doing anything relevant to ongoing classroom life, in this scenario. Some early interventionists even take the child out of the classroom and provide therapy or instruction totally out of sight of the teachers.

These one-on-one in classroom (McWilliam, 1996) or pull-out models prevent teachers from learning techniques they could use during all those hours when the early interventionist isn't in the classroom.

## Solutions

THESE 10 MISTAKES can be fixed by adopting five practices that constitute a natural-environments approach to early intervention (McWilliam & Er, 2003; Workgroup on Principles and Practices in Natural Environments, 2007). The five practices, described below, consist of constructing an ecomap, conducting Routines-Based Interviews (RBI), identifying a primary service provider, offering support-based home visits, and consulting collaboratively in the classroom.

### Ecomap

The first solution is to conduct an ecomap with the family at the intake visit. This will offset Mistake 1, talking too much, and Mistake 2, asking families repeatedly to talk about daily routines.

An ecomap is a drawing of the nuclear family and their extended family, friends, neighbors, professionals, agencies, recreation opportunities, employers, and religious groups. These are informal, formal, and intermediate supports (Ray & Street, 2005).

More important, perhaps, than the product is the process—the conversation between the intake coordinator and the parent, as the coordinator draws the map. As each member of the network is mentioned, the professional asks questions to determine the level of support (e.g., “How often do you talk to them?” “How well do you get along with her?” “Do you like him?”). Although when written down here, these questions might seem intrusive, families understand the general idea of constructing the ecomap. Their answers to the support level questions determine the thickness of the lines the professional uses to connect the network member to the nuclear family. The whole process takes only 10–15 minutes.

Ecomaps give the family the opportunity to talk about themselves, even if it's for just a short while. It counterbalances all the information the intake professional has to give—all that talking. Constructing an ecomap provides important information about the family, without getting into their routines. The intake coordinator is not asking about routines, knowing that, at a subsequent contact, the family will be asked about routines in a detailed way. Developing ecomaps therefore helps with Mistakes 1 and 2. For more information about conducting an ecomap, see McWilliam (2010b) and Ray and Street (2005).

### Routines-Based Interview

The solution to Mistake 3, basing goals only on what parents say they want, is to conduct an RBI with the family (McWilliam, Casey, & Sims, 2009). The interview typically is done between the determination of eligibility and the completion of the IFSP. The purposes of the RBI are to develop a positive relationship with the family, to obtain a rich and thick description of child and family functioning, and to obtain a list of family-chosen functional outcomes (goals) for the child and family.

The interviewer asks the family about their main concerns and then asks questions to gather in-depth information about what the family and child do during each time of the day (i.e., activity, event, routine). The questions are about what the whole family does; about the child's engagement, independence, and social relationships; and about the family's satisfaction with the routine. The interview ends with the interviewer reminding the family about the concerns or desires they mentioned in the discussion of each routine. The family then lists what they want to work on with the team—the outcomes—and they put them in priority order.

When parents are first asked what they want, they have little structure for answering. After going through an RBI, they have thought carefully through the functional needs of the



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**In many communities, services are decided upon on the basis of the child's diagnosis or what she cannot do.**

day and are well equipped to list 6–10 outcomes to go on the IFSP.

## FUNCTIONAL OUTCOMES

These outcomes are therefore highly functional for the child and family and must now be written in such a manner that progress and accomplishment can be measured (McWilliam et al., 1998). They address Mistake 4, which is ignoring the participation purpose of child-level outcomes or goals and skimping on the measurability of outcomes or goals.

The solution is found in seven steps of functional outcome writing:

1. Read the shorthand version of the outcome from a family-centered, functional needs assessment (e.g., RBI).
2. Find out what routines this affects.
3. Write “Child will participate in [the routine(s) in question]”.
4. Write “by \_\_\_\_\_ing,” addressing the specific behaviors.
5. Add a criterion for demonstrating the child has acquired the skill.
6. Add another criterion for generalization, maintenance, or fluency, if appropriate.
7. Add the amount of time given for accomplishing the goal.

An example of an outcome addressing play with toys during hanging-out times is “Tyrell will participate in hanging-out times at home by playing with toys. We will know he can do this when he plays with a toy for 5 minutes, independently, 3 times in 1 week.”

## Learn More

### MY EARLY INTERVENTION IN NATURAL ENVIRONMENTS BLOG

<http://naturalenvironments.blogspot.com>

My Early Intervention in Natural Environments blog covers a variety of topics on this issue. Recent posts have been about toddler groups, how to address autism from a natural-environments perspective, and the RBI with families of recent neonatal intensive care unit graduates.

### SISKIN CENTER FOR CHILD AND FAMILY RESEARCH

[www.siskinresearch.org](http://www.siskinresearch.org)

The Siskin Center for Child and Family Research conducts applied research on children's development and functioning to discover effective and innovative methods of intervention with children and families. This Web site has many resources related to the routines-based model.

### NATIONAL EARLY CHILDHOOD TECHNICAL ASSISTANCE CENTER

[www.nectac.org/topics/natenv/natenv.asp](http://www.nectac.org/topics/natenv/natenv.asp)

The Natural Environments page of the National Early Childhood Technical Assistance Center includes *Key Principles and Practices for Providing Early Intervention Services in Natural Environments*. The Technical Assistance Community on Part C Settings is found at [www.tacomunities.org/community/view/id/1029](http://www.tacomunities.org/community/view/id/1029)

### MISSOURI'S DEPARTMENT OF ELEMENTARY AND SECONDARY EDUCATION

[www.dese.mo.gov/divspeced/FirstSteps/EITEAMpage.htm](http://www.dese.mo.gov/divspeced/FirstSteps/EITEAMpage.htm)

The Early Intervention Teams page of Missouri's Department of Elementary and Secondary Education shows the history of Missouri's movement to teams, their definition of teams, various question and answer documents, and brochures.

### ORELENA HAWKS PUCKETT INSTITUTE

[www.puckett.org](http://www.puckett.org)

The Web site of the Orelena Hawks Puckett Institute contains many resources related to enhancing healthy child, parent, and family functioning. This is the institute Carl Dunst founded with his long-time collaborator, Carol Trivette.



PHOTO: MARILYN NOLT

### Working with adult family members builds intervention skills throughout the week.

Writing participation-based goals addresses directly the problem of goals that might address a skill but that don't improve a child's engagement (McWilliam & Casey, 2008) in a meaningful, normal routine. As shown above, the various criteria make the child-level outcomes highly measurable. With family-level outcomes, one criterion is usually enough. For more information about the RBI, see McWilliam (2010a, 2010b) and McWilliam et al. (2009).

### Primary Service Provider

Mistake 5 is matching services to deficits, leading to a pile-on of services, which is especially likely in states using a vendor approach to services. The solutions to this mistake are found in how service decisions are made, how services are provided, and the roles service providers are prepared to play.

### INCREMENTAL DECISION MAKING

This method of making decisions about services adds services only as necessary, rather than assigning a service to every need. The premise is that well-trained early interventionists can meet a variety of needs, not just a narrow set of needs aligned with their original training. The incremental decision-making procedure begins with the assumption that one professional is assigned to the child and family as the primary provider. The team then adds only services needed to address outcomes the primary provider and the family need additional help with. For example, if a child is delayed in talking, but the primary provider and

the parent know how to teach him to talk, there is no need to add an ongoing service. When a service is added, the team plans a level of intensity needed to ensure that the regular caregivers and the primary provider have the information necessary. These additional services are for information—it's a consultative approach—not working directly with the child. Even in a clinic, which is not a natural environment, the clinician needs to use the child as the vehicle for teaching the family how to intervene with the child. The child is getting intervention from regular caregivers, such as parents and teachers (McWilliam, 2003). Incremental decision making prevents the pile-on of services by adding only services that are necessary.

### ONE MAIN PROVIDER

Integrated services focus the support provided to families, rather than diffuse them across multiple professionals. Teamwork is ensured by having one professional through whom team members work, like a funnel. This person can be a regular home visitor, a classroom teacher, or a classroom consultant. When a funnel approach is not used, services are in silos (everyone doing his or her own thing, irrespective of others) or scattershot (disparate, unconnected people working with the same family). The primary-service-provider model is defined as one professional providing weekly support to the family, backed up by a team of other professionals who provide services to the child and family through joint home visits with the primary service provider. The intensity of joint home visits depends on child, family, and primary-service-provider needs.

The use of a primary service provider prevents the pile on of services by having one professional as the ongoing support who views the whole child and family, seeking help as needed. For more information about the use of a primary service provider, see Hanft, Rush, and Shelden (2004), McWilliam (2003), and Woodruff and Shelton (2006).

### Support-Based Home Visits

Four mistakes are addressed through support-based home visits:

1. Working directly with the child,
2. Modeling or demonstrating blindly,
3. Using the same home visiting approach for all families, and
4. Focusing exclusively on the child's well-being and quality of life.

Support-based home visits consist of providing emotional, material, and informational support (McWilliam & Scott, 2001). Suggestions are based on child and

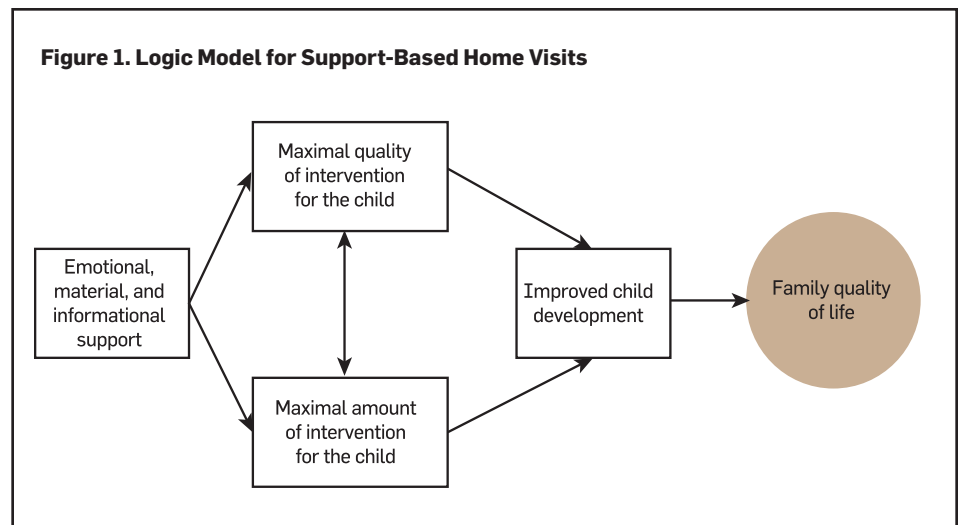
family functioning in routines and require a good set of functional outcomes. The home visitor goes down the list of 6-10 outcomes, in the family's priority order, although in any one visit perhaps only a few outcomes are addressed. To address each outcome, the home visitor gets the family's perception of how things have been going, determines what the family would like the child or family to be able to do during specific routines, listens for a discrepancy between the demands of the routine and the abilities or interest of the child, assesses what the family has already tried, gives information about potential interventions, assesses the family's interest in learning the specifics of the interventions, and, if the family is interested, teaches the intervention to the family. The Vanderbilt Home Visit Script (McWilliam, 2010b) can be useful in reminding home visitors to take a routines- and support-based approach. The script consists of the following questions:

1. How have things been going?
2. Do you have anything new you want to ask me about?
3. Review of outcomes in priority order.
4. Is there a time of day that's not going well for you?
5. How is [family member] doing?
6. Have you had any appointments in the past week? Any coming up?
7. Do you have enough or too much to do with [your child]?

By adopting the consultative approach inherent in these home visits, the home visitor works directly with the adult family members, rather than the child, so the family has the intervention skills to use throughout the week. Furthermore, talking to the parents makes sure that adult-level needs are also addressed. These home visitors use modeling as a technique only in the context of providing information to families and they customize each visit to the family's individual needs and preferences; this happens by getting the family's perceptions, determining what the family would like the child or family to be able to do, listening, assessing what the family has already tried, and so on. Finally, focusing on the results of the RBI and conducting home visits in such a family-centered manner allows the home visitor to focus on the family's quality of life. The logic model for support-based home visits is shown in Figure 1.

### *Collaborative Consultation to Child Care*

The tenth mistake, working only with children in classrooms, refers to classroom



consultants, including therapists, early interventionists, and itinerant teachers, who interact with children directly, hands-on. The solution to this mistake is to use a method that provides more intervention to the child—integrated services, focusing on services that are individualized within routines and group activities, two evidence-based approaches to consultation (Horne & Mathews, 2004).

Integrated specialized services are when therapy and special instruction occur in the classroom with other children usually present and in the context of ongoing routines and activities, when the teaching staff can learn from the consultant. The purpose is to ensure the teaching team has the knowledge and skills to be able to maximize the child's meaningful participation in everyday routines (Noell et al., 2005). Providing intervention that is individualized within routines is a technique in which the consultant joins the child in whatever the child is engaged in that is part of the regular classroom routines and weaves his interventions into that interaction. Group activity occurs when the consultant conducts an activity for the whole class or a group, for the benefit of an individual child. In both of these techniques, the teaching staff is present, watching, and helping, so they can learn the interventions to apply later on (McWilliam, 1996). The use of a collaborative, integrated approach to seeing children in child care involves working with adults in classrooms, often by demonstrating with children. For more information about collaborative consultation, see McWilliam (1996, 2010b) and Rush, Shelden, and Hanft (2003).

### **Discussion**

**T**HESE MISTAKES AND SOLUTIONS are consistent with the mission and guiding principles set out by the Workgroup on Principles and Practices in

Natural Environments (2007). I must self-disclose that I was part of that Workgroup. As stated previously, this collection of supposed experts in early intervention in natural environments arrived at the following mission statement: "Part C early intervention builds upon and provides supports and resources to assist family members and caregivers to enhance children's learning and development through everyday learning opportunities" (p. 2). Deconstruction of this statement makes some points apparent. First, early intervention should add to and strengthen the informal supports families of young children already have. It should not set up interventions in isolation of the resources families already have. Second, early intervention should ensure children and their families have access to information and actual materials that will foster child and family development. Information and materials can come through formal services (e.g., special instruction, physical therapy, occupational therapy, speech-language pathology), but early intervention should not be limited to services (Dunst, Trivette, & Deal, 1994). Third, early intervention was designed to assist the adults in a child's life, not the child. This distinction is a hard pill to swallow for many well-meaning early interventionists, who have devoted their careers to children or those who are afraid that this diminishes the amount of attention children will receive. As this article should have made clear, however, the point is that children will actually receive more help and more relevant help if interventionists support the adults. Fourth, interventionists are focused on the ultimate improvement of children's functioning. Adult competence and confidence are the proximal outcomes of the work (i.e., what interventionists directly affect) and child learning and development are the distal outcomes of the work (i.e., what interventionists affect as a function of adult competence and confidence). Fifth,

interventions should occur in naturally occurring places, in naturally occurring routines, and from the child's natural caregivers (e.g., parents, teachers). Urie Bronfenbrenner (1977) wrote, "much of contemporary developmental psychology is the science of the strange behavior of children in strange situations with strange adults for the briefest possible periods of time" (p. 257). Although he was writing about research, the same could be said for they way many early intervention services are provided. Children do become used to their weekly early interventionists, so those people are no longer

strange adults, but the Part C point is that such services are both too little (in terms of amount of intervention for the child) and too much (in terms of frequency and intensity of so many services, requiring family time). Better to follow the mission of early intervention and boost up everyday learning opportunities. ♠

**ROBIN MCWILLIAM, PhD**, is the director of the Siskin Center for Child and Family Research; the Siskin Endowed Chair of Research in Early Childhood Education, Development, and Intervention; and a professor at the University of

Tennessee at Chattanooga. Dr. McWilliam is one of the nation's leading researchers in early intervention/early childhood special education (EI/ECSE). He is the foremost investigator of engagement in children with disabilities and is the author, with Amy Casey, of the premier book on child engagement, *Engagement of Every Child in the Preschool Classroom*. Dr. McWilliam is the past president of the Council for Exceptional Children (CEC) Division for Research and is on the steering committee for CEC's efforts to define and identify evidence-based practices in special education.

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# A Community-Based Response to Part C

## *A Community Embraces Its Most Vulnerable Children*

JOAN MALTESE

JOANNIE AGUAYO

JOSE CHAVEZ

*Child Development Institute  
Canoga Park, California*

The Child Development Institute (CDI), located in North Los Angeles County's San Fernando Valley, has been providing comprehensive, family-centered early intervention services to local young children and their families for more than 16 years. Our range of early intervention services—funded through Part C of the Individuals With Disabilities Education Improvement Act of 2004 (IDEA, 2004)—include developmental assessment, parent support, relationship-based behavioral therapy, physical and occupational therapies, speech-language therapy, and service coordination for children up to 3 years old who have developmental delays. In addition, CDI serves as a training institute for transdisciplinary intervention, providing training opportunities for current professionals, as well as professional development and research opportunities for pre- and postgraduate students in child development fields.

Early intervention services are essential to help ensure young children with developmental delays or challenges reach their optimal developmental potential and are prepared for success in school and in life. Such services help children acquire the social-emotional, cognitive, language, and motor skills they need for a lifetime and are critical for reducing or preventing more severe developmental challenges. Studies have concluded that when developmental delays; disabilities; and behavioral, socio-emotional, and learning problems in young children are identified and addressed prior to kindergarten, such challenges can be addressed more effectively and at a potential savings to society of between \$30,000 and \$100,000 per child as children avoid placement in expensive special education programs altogether (Pinto-Martin,

Dunkle, Earls, Fliedner, & Landes, 2005). When children receive prompt intervention to treat developmental delays or challenges, they are better prepared for school, resulting in enhanced academic success; reduced high-school dropout; enhanced prospects for employment, health, and financial stability; and enhanced life outcomes (Karoly, Kilburn, & Cannon, 2005).

Despite extensive research showing the significant benefits that early intervention provides children with developmental delays or challenges, most children who need such services do not receive them. Approximately 13% of children in the United States are eligible for early intervention through Part C of IDEA, yet less than 10% of those children are receiving services (Rosenberg, Zhang, & Robinson, 2008).

### Vulnerable Children in Canoga Park

CDI'S SAN FERNANDO Valley service area covers more than 50 square miles of northern Los Angeles County. Local residents come from a wide range of socioeconomic backgrounds and life

#### Abstract

The Child Development Institute, a nonprofit early intervention program in California, conducted a needs assessment which revealed a community that was receiving little support for infants and toddlers. There was virtually no enrollment in Part C early intervention services despite ranking high on environmental risk factors. This article describes how a project engaged parents in common community settings such as shopping areas, local events, and a farmers' market to screen infants and toddlers for disabilities. Families became familiar with the ongoing screening activities and took advantage of the opportunity to talk about their child's development while their children played. Child care providers were recruited to administer regular developmental screening to children in their care and to continue the dialogue with parents regarding their children's development.



**Some parents were hesitant to have their child screened because they believed that screening was only for children who had “problems.”**

circumstances. Although the median household income is higher than other areas in Los Angeles County, the area also includes some of the most impoverished areas in the county. And while the San Fernando Valley is known for its low-density sprawl, it is also home to some of the most dense census tracts in the county.

In an effort to better understand how we could best meet the needs of local infants and young children, CDI conducted a focused needs analysis of our service area. This analysis revealed a pattern of significant gaps in services for different neighborhoods throughout the San Fernando Valley. For example, while nearly 75% of the families referred to CDI by our local regional center (see box California’s Regional Centers) lived within 15 miles of our site, less than 1% of our referrals came from one of the closest

neighborhoods, Canoga Park—just 1 mile away. We discovered that certain enclaves within nearby neighborhoods were accessing virtually no early intervention services. By contrast, other nearby neighborhoods—especially those with greater affluence and family educational attainment—were overrepresented in our referrals.

We also learned that low-income Latino children in Canoga Park face significant environmental factors that increase their risk for developmental delays and future academic failure. The combined risks of poverty, developmental delays, and low educational attainment increases a child’s risk of ending up on the “cradle-to-prison pipeline” (Children’s Defense Fund, 2007, p. 3). Of all children less than 5 years old living within the geographical boundaries of Canoga Park, 31% live in poverty (Los Angeles County Children’s Planning Council, 2006) and 60% are Latino. Of adults more than 25 years old, 57% have only a high-school diploma or less (U.S. Census Bureau, 2000). In addition, we found that there is a dearth of high-quality early care and education programs for young, low-income children in Canoga Park.

In 2008 we conducted a small developmental screening event at a health fair in Canoga Park. More than 85% of children screened at this event had two or more predictive indicators for developmental delays or disorders out of a total of 10 possible concerns as indicated by the Parent’s Evaluation of Developmental Status (PEDS; Glascoe, 1999). The PEDS is a valid and reliable 10-question instrument which asks parents questions related to their child’s

development (for the list of questions see [www.pedstest.com](http://www.pedstest.com)) These data indicated that these children were at risk and in need of referral for additional assessment by a child development professional, confirming the critical need for early developmental screening in Canoga Park.

CDI then set out to understand the best way to engage local families. We participated in local events, health fairs, and community planning groups, as well as with the local neighborhood council and Chamber of Commerce. We also developed relationships with existing local entities including faith-based groups, health clinics, WIC, Head Start, women’s groups, the police department, and the Community Redevelopment Agency of the City of Los Angeles. These groups are our community partners in identifying opportunities to develop long-term, community-based support to local families with young children.

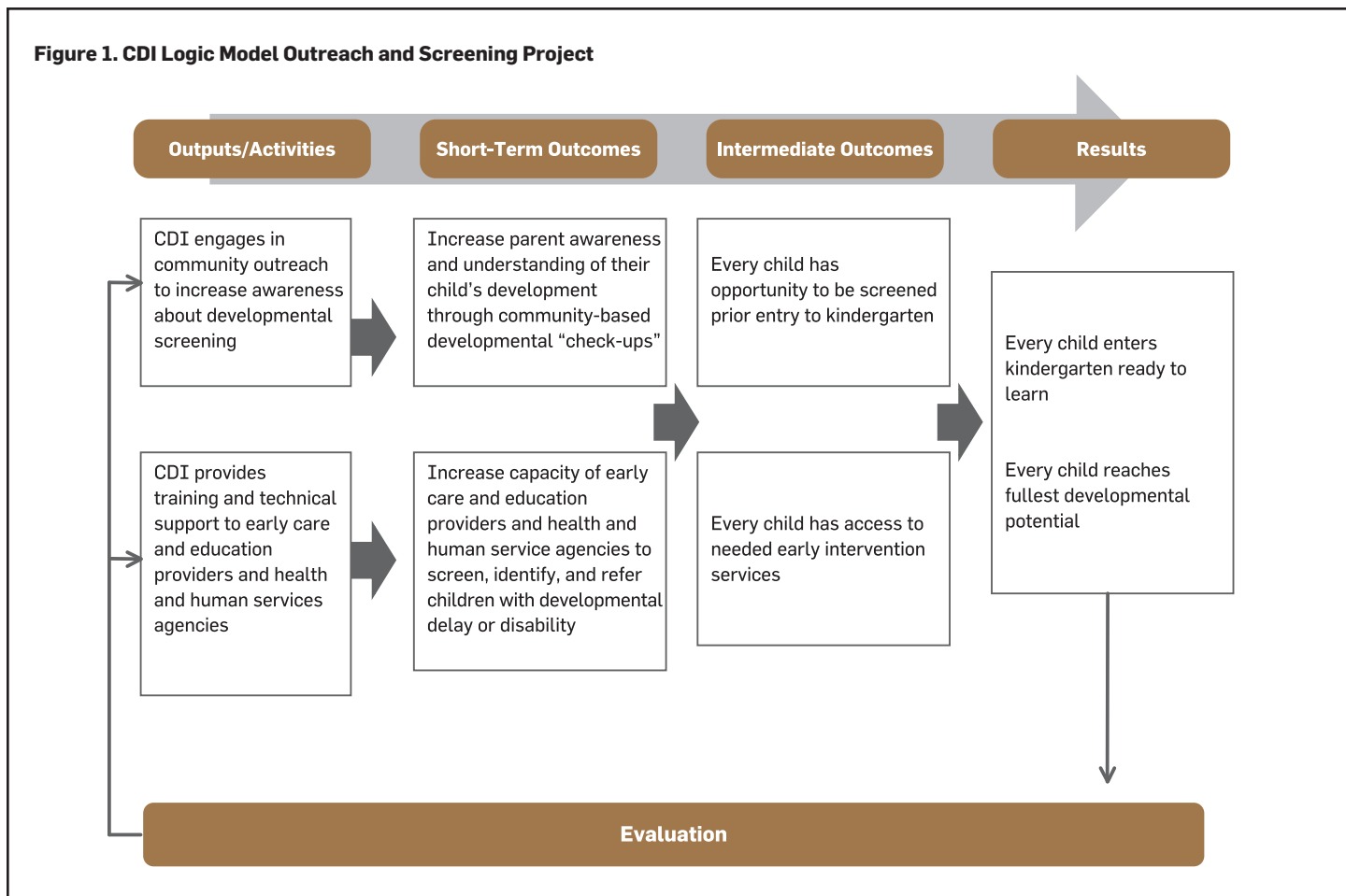
Over the course of our grassroots relationship-building activities in Canoga Park, we discovered a tight-knit community that welcomed our involvement and inquiry about their children. Scores of conversations with local residents suggested that many families did not know early intervention services existed. Many parents told us that they relied on family members for support and did not see the need for outside or professional support for their young children. When asked if they would be interested in early intervention services many said that they did not want to use government help unless absolutely necessary and that going to CDI’s clinic—even though it was just 1 mile away—was not appealing because it was out of their neighborhood and too formal. However, families were open to sharing concerns about their school-aged children who were struggling academically, and they expressed frustration that they did not know the best way to help their children.

Families need and want information about early development and the importance of early intervention. This support would be most effective if the information came from people they already knew and trusted. We decided to create a program to engage parents in conversation about their children’s development and to increase families’ awareness of available resources including prevention and early intervention services. We developed a logic model to illustrate our desired outcomes for the program and the activities needed to achieve these outcomes (see Figure 1). Our Outreach and Screening Project was born. CDI received generous grants from the Annenberg Foundation, the CVS Caremark Charitable Trust, and the Harold R. and Winifred R. Swanton Foundation to fund the project.

## CALIFORNIA’S REGIONAL CENTERS

The California Regional Center system is the nonprofit corporation that contracts with California Department of Developmental Services to coordinate early intervention services for children from birth to 3 years old under IDEA Part C and services to individuals from 3 years old to death who have serious developmental challenges such as autism, cerebral palsy, epilepsy, and mental retardation. There are 7 regional centers in Los Angeles County and 21 centers statewide.

**Figure 1. CDI Logic Model Outreach and Screening Project**



## The Outreach and Screening Project

**T**HE PURPOSE OF the Outreach and Screening Project is to ensure that every child in the community served has the opportunity to enter kindergarten ready to learn and to achieve her fullest developmental potential. Over the long term, we seek to build systemic and programmatic cross-agency and parent partnerships to increase community capacity to sustain screening activities throughout the community.

To achieve this goal, we knew we needed to ensure that all local children had the opportunity to receive both a developmental screening and any needed early intervention services. As a starting point, CDI proposed the bold goal of screening 1,000 young children from the Canoga Park community over a period of 12 months by conducting the following activities:

1. Hold community-based "developmental checkups" (screening events) in locations frequented by local families to engage parents in discussions regarding their children's development and to screen local children for developmental delays or challenges

2. Train local early child care and education (ECE) and human service agencies to screen and identify children with developmental disabilities.

### Community-Based Screening Events

To increase community awareness of early development in a natural and nonthreatening manner, CDI held community-based screening events that engaged local families where they live, learn, and play. Screening events were held at high-traffic community locations such as a local shopping mall, the farmers' market, a CVS pharmacy, and health fairs.

At each event CDI set up a screening booth and bilingual team of CDI staff and volunteers recruited directly from the Canoga Park community and trained by CDI to engage families and screen young children. All screeners used the Parents Evaluation of Developmental Status (PEDS; Glascoe, 1999). As families came to our screening booths, team members engaged parents in conversations regarding their children's development and offered information in both English and Spanish regarding important developmental milestones and early warning signs of developmental delays. Parents were invited to complete the PEDS on their own or with a trained screener. Child-friendly games and

activities were provided by trained volunteers while parents met with one of the screeners. Families were given as much time as they wanted to discuss concerns with the screener. Families were also offered a follow-up consultation by phone, to discuss assessment results and next steps, as well as assistance with getting appropriate resources.

Our screening booths helped parents to identify their child's specific areas of concern and gave parents the opportunity to learn more about their child's developmental age and stage. Parents wanted to know whether their child was developing typically or if there were warning signs of future problems.

We also found that that some parents were hesitant to have their child screened because they believed that screening was only for children who had "problems," and they did not believe their child had problems. To diminish stigma related to developmental screenings, CDI informed families of the American Academy of Pediatrics' recommendations that all children receive developmental and behavioral screenings at 9 months, 18 months, and 24–30 months using a standardized screening tool (American Academy of Pediatrics, 2006). Many parents were surprised to learn this, as most of their children had never received a developmental

screening. Parents were able to revise their perspective to see that screening is something that all children should receive, not just children suspected of having special needs.

### **Results of Screening Events**

CDI directly screened 215 children ranging from 5 months to 9 years old. We consulted with hundreds of families through nine separate events in the Canoga Park community.

Of the 215 children screened, 99 (46%) were reported to have one or more indicators for a developmental delay or challenge. Parents of these children received information about resources for full assessment and intervention services.

While the remaining families reported no significant concerns, many of these parents had questions about their child's development that they had not been able to discuss with a health care provider. Family concerns were related to typical developmental ages and stages, such as tantrums, toilet training, not "listening" to parents, sleeping, eating, getting along with other children, and when and how to choose a good preschool program for their child.

Many families requesting assistance had already made attempts to contact their local school district to evaluate their child, but reported that school personnel dismissed these requests as being unnecessary (e.g., their child was not eligible or was not having learning challenges). This situation was common for children older than 5 years and whose parents were recent immigrants to California, primarily monolingual, and

Spanish-speaking. This finding is consistent with a study conducted by Lakes et al. (2009) that investigated the underutilization of early intervention services by Latino families. Their results demonstrated that children whose families are low-income, Spanish-speaking, and lack legal immigration status are less likely to access and receive services for their child.

### **Successes**

One of our greatest successes was a screening event at the local mall. We were able to reach 79 families over one weekend. We were pleased to find young parents, both mothers and fathers, at ease and eager to share. By creating a space that allowed children to play safely under adult supervision, parents were able to spend up to 45 minutes deeply engaged in discussions about their children. Many asked if we would be there regularly.

On numerous occasions, grandparents and educators have approached our screening booth team to thank CDI for offering developmental screening and information in the community. Many of them returned later with their friends and family to have their children screened.

CDI made a substantial impact by empowering families with information about their legal rights and early intervention services to which their child is entitled. One family had been trying to have their 2-year-old assessed by the regional center for more than 2 months but had been experiencing numerous roadblocks. Our staff was able to intercede on

behalf of this child, resulting in the family being able to arrange for an assessment within 2 weeks of their conversation with one of our screeners.

CDI continues to offer screening events in the immediate community of Canoga Park and the immediately surrounding communities which also have high numbers of low-income Latino families with young children. We currently hold "developmental checkup days" twice a month at the local farmers' market in Canoga Park.

### **Challenges and Barriers**

One of the greatest barriers was difficulty reaching parents who requested follow-up consultation by phone. Although we called 100% of the 54 families who requested a follow-up contact from CDI to discuss screening results and to receive further information regarding resources and services available, 40% of these families were not reached because the contact numbers they provided were incorrect or disconnected. And several attempts were necessary for those families we did reach. Even after receiving information and instruction regarding where and how to access supports for their child, many families found the procedures to be overwhelming and frustrating, especially those families that speak limited English or are recent immigrants to the U.S.

Recently, our local regional center has developed an online process for families or providers or both to make referrals for assessment and intake. We plan to bring laptops to our screening booths in the future so that referrals can be made directly. CDI believes that this process can significantly increase the number of families who move from identification to referral, assessment, and services as needed for their child, reducing the number of children who fall through the cracks.

### **Training Local Agencies**

**T**O FURTHER EXPAND the availability of screening for Canoga Park children, and to ensure that delays are identified as early as possible, CDI brought screening to additional locations where children already go: local day care centers, preschools, and family service agencies. CDI recruited staff to receive training by identifying all day care and preschool programs within Canoga Park. We reviewed resource lists, drove through the community, and followed-up on word-of-mouth referrals from other providers. We then contacted each organization through in-person visits or through informational mailings. CDI subsequently trained 12 child care centers or preschools and one family services agency. Specifically, we provided 6 hours (three 2-hour sessions) of training to 39



PHOTO: MARILYN NOLT

**A critical key for success in recruiting child care centers is building relationships with directors and teachers prior to, during, and after training.**

staff members. Each agency was provided an introduction to the Strengthening Families approach (see Learn More box) and training in either of two high-quality, research based developmental screening tools: the PEDS or the Ages & Stages Questionnaires-3 (ASQ-3; Squires & Bricker, 2009). After the initial training, CDI provided follow-up support and consultation to each organization to ensure that their staff achieved an adequate level of competency in using the screening tools and that they had the capacity and capability to help families navigate systems of care to obtain needed intervention services.

### Results of Local Agencies Trainings

CDI measured the effectiveness of our training sessions using a pre- and post-test survey of participant's perceptions of their confidence and competency in (a) administering the selected screening tool and (b) discussing atypical development and results with parents.

As shown in Table 1, prior to training, 47% of participants felt either "somewhat" or "definitely" comfortable with speaking about a child's developmental concerns with a parent. After receiving training, 85% felt that they would be comfortable discussing a child's developmental challenges with a parent.

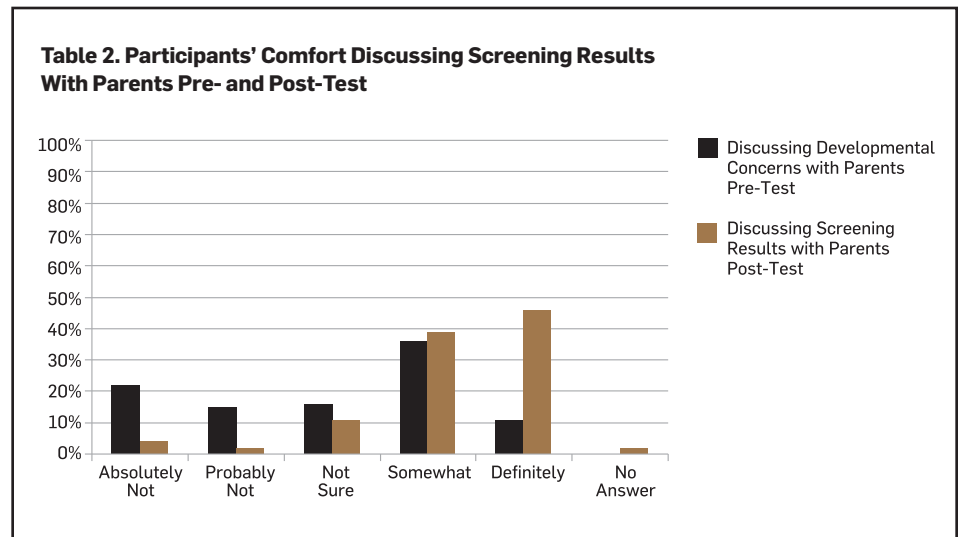
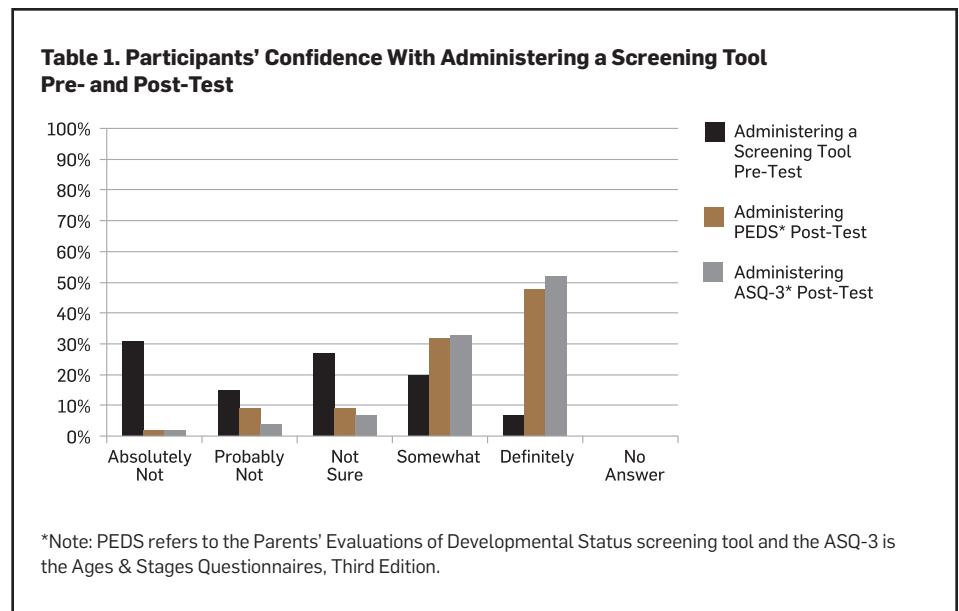
Prior to training, only a minority of participants perceived themselves as being either "somewhat" (20%) or "definitely" (7%) comfortable with administering a screening tool (see Table 2). In contrast, one third of participants reported feeling "somewhat" and one half "definitely" comfortable with administering either the PEDS or the ASQ-3 after training and follow-up.

### Successes

We expect our partner agencies to screen 580 infants, toddlers, and preschoolers in the year following their training. CDI is currently in the process of conducting follow-up for children as they are screened to ensure they receive the resources and referrals they need. Surveys completed by partner-agency staff after the training indicated high levels of satisfaction with their training experience (see box Participant Evaluation of Training). However, providers also reported that they were unsure about whether screenings could be done universally. We are in the process of following up with each of our partner agencies to understand what support they need in order to implement universal developmental screening to the children they serve.

### Challenges and Barriers

Recruitment of child care and preschool centers to participate in our training sessions proved to be more challenging than



anticipated, even though trainings were free of charge to participants. We had a higher response rate from agencies that we contacted in-person than from those we contacted via mail. Some agency directors were apprehensive about signing Memoranda of Understanding that allowed CDI to follow up on the extent to which they were using the screening tools and the manner in which they were using this information. We have concluded that a critical key for success in recruiting child care and preschool centers is building relationships with directors and teachers prior to, during, and after training. This is especially important for achieving the desired goal of creating a culture of universal screening within early childhood programs. We must remain sensitive to each site's individual needs in order to ensure their participation.

Another challenge we encountered in recruiting community agencies to participate in our training was the lack of substitute teachers or funding to compensate staff for

### PARTICIPANT EVALUATION OF TRAINING

Surveys completed by partner-agency staff after the training indicated high levels of satisfaction with their training experience. Respondents reported that the information:

"...would help tremendously in evaluating where a child lands in their age group and how to best assist the child."

"...was very informative and beneficial for staff and clients...this information should be in hospitals and schools as standard resources."

"...helped to reinforce some of the things we already do and gave us some tips and ideas for things we can start looking for and addressing with parents."



**Providing developmental screenings in community locations is a way to engage parents in conversations about their children's development.**

## Learn More

### FIRST SIGNS

[www.firstsigns.org](http://www.firstsigns.org)

### NATIONAL DISSEMINATION CENTER FOR CHILDREN WITH DISABILITIES (NICHCY)

[www.nichcy.org](http://www.nichcy.org)

### NATIONAL EARLY CHILDHOOD TECHNICAL ASSISTANCE CENTER (NECTAC)

[www.nectac.org](http://www.nectac.org)

### OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES (OSERS)

[www2.ed.gov/about/offices/list/osers/index.html?src=oc](http://www2.ed.gov/about/offices/list/osers/index.html?src=oc)

### STRENGTHENING FAMILIES

[www.strengtheningfamilies.net](http://www.strengtheningfamilies.net)

### Screening Tools:

#### PARENTS' EVALUATION OF DEVELOPMENTAL STATUS (PEDS)

- PEDS: Developmental Milestones (PEDS:DM)
- PEDS Online

[www.pedstest.com](http://www.pedstest.com)

#### THE AGES AND STAGES QUESTIONNAIRES

- Ages and Stages Questionnaire- 3rd Edition (ASQ-3)
- Ages and Stages Questionnaire- Social Emotional (ASQ-SE)

[www.agesandstages.com](http://www.agesandstages.com)

#### Community Capacity Building:

##### KIDS COUNT

[www.aecf.org](http://www.aecf.org)

##### SUSTAINABLE MEASURES

[www.sustainablemeasures.com](http://www.sustainablemeasures.com)

release time to attend the trainings. We were able to address part of this challenge by offering training sessions on days and at times that do not interfere with teacher and staff schedules. In the future, we would like to offer attendance scholarships for teachers who do not receive compensation for release time or to centers to offset costs that may be incurred from hiring substitutes to replace staff who attend training. This will emphasize the value of having better trained staff.

Among the barriers to implementing screenings at our partner agencies' sites, agency staff report that language or cultural barriers between staff and families; parental reluctance to have their children screened; and lack of time, staffing, and space to conduct screenings have hindered implementation. To address these issues, CDI has already begun offering technical assistance to agencies that received initial training. We also plan to offer continued training opportunities in the Strengthening Families approach which will help agency staff build trusting relationships with families of the children in their care.

## Discussion

**T**HE CDI OUTREACH and Screening Project in Canoga Park was highly successful in increasing community awareness regarding early development and how and where to get supports for children with developmental delays or challenges. Through our community-based screening events we screened 215 children. Our partner early child and education and human service agencies will screen up to 580 children (depending on the number of children enrolled in participating programs) over the next year.

CDI's work has not been limited to screening children and making referrals for services. We view providing developmental screenings in the community locations as a way to engage local parents in conversation about their children's development and to create relationships with community members on the basis of our shared interest in their children's well-being. Our goal was to empower families with knowledge and resources and build the community's capacity to promote healthy early development—so that parents and the community are equipped to provide optimal care and opportunities for their children.

Prior to launching our Outreach and Screening Project in Canoga Park, we spent 3 years becoming involved in community activities and listening to the needs of local families with young children. We learned about strengths and vulnerabilities, the goals of the business community, and the local infrastructure of social and human services. The process worked both ways: local residents learned about CDI and about our commitment to children's healthy development. They got to know our staff and came to expect our involvement in matters related to young children. Their children looked forward to participating in the activities and games at our booths. This level of mutual trust laid the groundwork for the effectiveness of our Outreach and Screening Project.

Today, at the Canoga Park farmers' market, families continue to stop by our booth on a regular basis. A local mother who visits regularly with her son, Diego, told a CDI staff member that she comes as often as possible because her son "looks forward to seeing Jose," a CDI screener, and because she feels she gets "extra support" for herself. Many local families bring their friends by to meet our team or to have their children play, and some even bring homemade treats to show their appreciation. Others volunteer to help at our booths.

Local families and other community members are also playing an important role in the planning of a new early learning center at site of the former Canoga Park library. The center will provide a drop-in play center. Embedded within play and learning spaces will be an array of high-quality early childhood development services and professional interventions. The Community Redevelopment Agency of the City of Los Angeles, the local neighborhood council, and the Chamber of Commerce supported a decision to dedicate the former library site to serve the needs of families with young children. CDI's partnerships with Child Care Resource Center and Providence Health Services will provide developmental screening, family resources, early education, and other services as needed.

The relationships we have developed with local child and family service agencies in the

area resulted in enhanced community capacity to provide information and resources to families with infants and young children. These providers see hundreds of Canoga Park children each year and interact with local families daily. They are essential players in reaching local families and ensuring that all children in their care—now and into the future—receive regular screening for developmental delays. Individual teachers who receive our training will take this knowledge with them to future positions at other agencies, thereby expanding screening capacity beyond Canoga Park.

CDI intends to continue to build on the successes already achieved through our Outreach and Screening Project. To date, we have identified program components and methods that work and others that have not. We will make adjustments to ensure our ability to reach our goal of establishing a systematic Outreach and Screening Program,

available to every Canoga Park child, providing for prompt identification and thus early access to intervention for all children with special needs. ♻

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**JOAN MALTESE, PhD**, is executive director and co-founder of Child Development Institute. She is a clinical psychologist with more than 30 years experience working with high-risk infants, toddlers, and their families. She participates on several early care and education workforce development committees in California. She helped to develop the certificate program in Infant Toddler Family Mental Health for the early care and education graduate program California State University, Northridge, where she is also a faculty member.

**JOANNIE AGUAYO, EdD**, is community programs manager at Child Development Institute. She researches and develops community resources

and manages data collection and evaluation. She is on the faculty of California State University, Northridge in the Department of Child and Adolescent Development where she teaches courses in advanced child development theory and child advocacy. Dr. Aguayo also develops curriculum and training programs in for multiple organizations in California.

**JOSE CHAVEZ** is the volunteer coordinator for CDI's new early learning center in Canoga Park. He is a member of the Canoga Park community and works with family members and community leaders to access resources for families with young children. Jose is a graduate student in the Special Education Department in the College of Educational Psychology at California State University, Northridge.

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# Access, Participation, and Supports

## *The Defining Features of High-Quality Inclusion*

VIRGINIA BUYSSE

*FPG Child Development Institute, University of North Carolina at Chapel Hill*

*My son has been enrolled in an inclusive child care setting for almost a year now. He is 3 years old and has a rare chromosomal abnormality. To be honest, I hadn't even heard of inclusion before I found out about this school. I figured he would attend some sort of special school. And that's what I thought would be best for him. Surrounded by well-trained staff who would work one on one with him, I couldn't think of a better way for my son to be educated. But then I learned about inclusion, and well, it just clicked. Of course that would be better for my son, better for everyone in fact. OK, I'm sold.*

Lindauer, 2009

These words were written by the mother of Luke, a young child with disabilities. She is the author of a blog called *Christine's Chronicles* in which she shared her first-hand experiences with inclusion, beginning with the realization that inclusion might be a better approach for promoting her son's development and learning than placing him in a specialized program. Later in the same blog entry, Christine reflected on the meaning of the words *access*, *participation*, and *supports* 1 year after enrolling Luke in an inclusive program. She concluded that although the access and support components were in place on day one, the participation component was not as effective for Luke as she had hoped it would be. As evidence, she observed that her son often played in a corner by himself or stared off during circle time when the other children were engaged in fun, learning activities. What is notable and perhaps even remarkable about these musings is that a mother of a young child with disabilities was using concepts that convey the precise meaning of her experience with different aspects of inclusion. Furthermore, others who have a shared understanding of these terms can easily translate Christine's words into a plan to improve the quality of her son's inclusive program. They would immediately understand, for example, the need to help Luke's teachers identify new instructional and intervention practices that would create more opportunities for Luke to engage in learning activities and interact in a more meaningful way with the children and adults in his environment. But where did the terms *access*, *participation*, and *supports* come from? What do they mean exactly? And how can these ideas help others in the field who are interested in promoting quality inclusive practices?

This article describes current knowledge about early childhood inclusion, summarizing research and the DEC/NAEYC joint position statement on inclusion (DEC/NAEYC, 2009). The position statement was designed to identify specific educational practices that promote access, participation, and supports—the defining features of high-quality inclusive services for young children with disabilities and their families (Buysse, in press). This information can be used to advocate for quality inclusive services, to support program quality improvement efforts, and to advance knowledge and understanding on these issues.

### **Abstract**

**This article describes current knowledge about early childhood inclusion, summarizing research and the DEC/NAEYC joint position statement on inclusion. The article also describes effective or promising educational practices that promote access, participation, and supports—the defining features of high-quality inclusion. Future efforts to improve the quality of inclusion must begin to connect these research-based practices in early care and education settings with systems-level supports related to the broader program quality movement.**



## Research on Early Childhood Inclusion

**R**ESearch on early childhood inclusion in the U.S. stretches over a period of more than 30 years. The National Professional Development Center on Inclusion (NPDCI; 2009) summarized what is currently known about early childhood inclusion, drawing on published articles, books, critical reviews, and syntheses on this topic (Buyse & Hollingsworth, 2009; Guralnick, 2001; Odom, 2002; Odom et al., 2004). The summary offered succinct conclusions from this body of literature, referred to as research synthesis points, along with a list of references to support each of the key conclusions. Rather than being an exhaustive review of the literature, the NPDCI summary provided the most current and representative studies on specific topics related to inclusion to support the broad conclusions drawn from this body of research (see NPDCI, 2009, for a complete list of supporting references). The research synthesis points are the following:

### 1. Inclusion takes many forms.

Inclusion can occur in a wide variety of organizational and community contexts (e.g., homes, child care, Head Start and Early Head Start, recreational programs, pre-kindergarten programs). Further, there are many ways in which inclusive services can be designed and implemented (e.g., itinerant services, blended programs, co-teaching, home visiting, family supports, community-based services).

**2. Universal access to inclusive programs for children with disabilities is far from a reality.** According to the most recent annual report to Congress in 2007, approximately 48% of children from 3 to 5 years old with disabilities spend at least 80% of their time in an inclusive setting with typically developing peers, while 25% receive services in specialized or self-contained settings (U.S. Department of Education, 2010). The vast majority of infants and toddlers (approximately 82%) receive early intervention services through home visiting, while approximately 3% of these children receive services in other types of settings that also serve typically developing peers.

**3. Inclusion can benefit children with and without disabilities.** There is strong research evidence that shows that children with disabilities enrolled in inclusive settings make at least as much developmental progress as they do in non-inclusive settings. Furthermore, there is some evidence to suggest that children with disabilities in inclusive programs make greater progress in the area of

social development, communication, and perhaps play.

**4. Factors such as child characteristics, policies, resources, and attitudes influence the acceptance and implementation of inclusion.** This body of research suggests that beliefs and practices related to inclusion are based on many factors (e.g., the nature and severity of a child's disability, professional attitudes toward inclusion, parental preferences for various program types), and that all of these factors can influence how well inclusion is accepted and implemented.

**5. Specialized instruction is an important component of inclusion and a factor affecting child outcomes.** A variety of research-based instructional strategies such as curricular modifications, peer supports, and embedded interventions exist to support child development and learning in the context of inclusion.

**6. Collaboration among parents, teachers, and specialists is a cornerstone of high-quality inclusion.** Collaboration has been identified as an essential component of high-quality inclusion by families and professionals. Promising models for effective communication and collaboration described in the literature include technical assistance, consultation, coaching, mentoring, and teaming.

**7. Families of young children with disabilities generally view inclusion favorably, although some express concerns about the quality of early childhood programs and services.** Although most families have expressed positive attitudes toward inclusion and report that their children have benefitted from inclusion, some have identified specific concerns related to inclusion (e.g., teachers may not be adequately prepared to work with children with disabilities, children with disabilities may not receive individualized attention and supports to promote learning and positive peer relationships).

**8. The quality of early childhood programs that enroll children with disabilities is as good as, or slightly better than, the quality of programs that do not enroll these children.** Much of the research supporting this conclusion was based on general measures of program quality. Few studies have evaluated the quality of programs on the basis of inclusive practices for individual children with disabilities and their families.

**9. Early childhood professionals may not be adequately prepared to serve young children with disabilities and their**



PHOTO: JANET MCCracken STIVERS

**The vast majority of infants and toddlers receive early intervention services through home visiting.**

**families in inclusive programs.** The little research evidence that exists in this area suggests that few early childhood teacher education programs require one or more courses in working with children with disabilities.

## Defining High-Quality Inclusion

**I**N 2009 THE Division for Early Childhood (DEC) of the Council for Exceptional Children (CEC) and the National Association for the Education of Young Children released a joint position statement on early childhood inclusion (DEC/NAEYC, 2009). Facilitated by NPDCI, the process of developing and validating the joint position statement included multiple opportunities for members of both organizations and the field at large to provide input and feedback (Buyse, Hollingsworth, & Catlett, 2009). The joint position statement was a historic event because prior to this the lack of a shared definition of inclusion (see box The Definition of Inclusion) had contributed to misunderstandings and served as an obstacle to reaching agreement on what types of services and supports were necessary to implement high-quality inclusion in ways that were consistent and predictable across different contexts.

### *Using the Joint Position Statement on Inclusion to Shape Policies and Practices*

In addition to providing a definition of inclusion, the DEC/NAEYC (2009) joint position statement provided six



**Assistive technology devices should be used to promote children's successful participation in everyday activities and routines.**

recommendations for how the statement can be used by families and professionals alike to shape educational policies and practices that support high-quality inclusion. These included:

1. **Create high expectations for every child to reach his full potential.** The joint position statement (DEC/NAEYC, 2009) was

## THE DEFINITION OF INCLUSION

The DEC/NAEYC (2009) joint position statement defined inclusion in the following way:

*Early childhood inclusion embodies the values, policies, and practices that support the right of every infant and young child and his or her family, regardless of ability, to participate in a broad range of activities and contexts as full members of families, communities, and society. The desired results of inclusive experiences for children with and without disabilities and their families include a sense of belonging and membership, positive social relationships and friendships, and development and learning to reach their full potential. The defining features of inclusion that can be used to identify high quality early childhood programs and services are access, participation, and supports. (p. 2)*

designed to assist families and professionals in their efforts to advocate for young children with disabilities. Having shared expectations that every child should reach his potential was described as the first step in selecting appropriate learning goals and ensuring that families and professionals reach consensus on the best way of organizing services and supports to accomplish them.

2. **Develop a program philosophy on inclusion.** As part of an overall mission statement, programs were advised to develop a program philosophy on inclusion to ensure that program staff operate under a similar set of assumptions, values, and beliefs about the best ways to support the development and learning of children with disabilities in the context of inclusion. It was suggested that agreement on these broad-based principles would lead in turn to the identification of specific teaching and intervening practices to support high-quality inclusion.

3. **Establish a system of services and supports.** Reaching consensus on the meaning of inclusion was intended to inform the creation of a continuum of services and supports that respond to the individual characteristics and needs of children with various types of disabilities (including children at risk for learning difficulties) enrolled in early care and education programs. Services and supports such as home visiting programs, itinerant services, family support, specialized programs and interventions, therapies, assistive technology, and specialized equipment and technology should be coordinated and integrated within general early care and education programs.

4. **Revise program and professional standards.** The joint position statement (DEC/NAEYC, 2009) can be used to expand existing standards that primarily reflect the needs of the general population of young children and families to incorporate the defining features of inclusion (i.e., access, participation, and supports) that identify dimensions of quality inclusive programs and the competencies of professionals who work in these settings.

5. **Achieve an integrated professional development system.** The joint position statement (DEC/NAEYC, 2009) was intended to help designers determine who would benefit from professional development, what practitioners need to know and be able to do, and how learning opportunities could be organized and delivered as part of an integrated professional development system to produce the desired results for children and families.

6. **Influence federal and state accountability systems.** The joint position statement (DEC/NAEYC, 2009) was intended to influence federal and state accountability standards. Policymakers were encouraged to move away from requiring states to report annually only the number of children with disabilities who received services in inclusive settings to emphasizing instead the quality and intensity of the services experienced by children and families and the outcomes of these services.

## Practices That Promote Access, Participation, and Supports

THE DEC/NAEYC (2009) joint position statement on inclusion offered the early childhood field clear, consensus wisdom on the meaning of inclusion and the defining features (access, participation, and supports) that distinguish high-quality inclusive programs, services, and supports from those that do not reflect these features. But the position statement accomplished even more. It identified particular practices that could be used to promote access and participation of young children and families in the context of inclusion, and the kinds of infrastructure supports necessary to support the implementation of inclusion system-wide. The following sections present an overview of specific practices related to access and participation that have empirical evidence of effectiveness or show promise in this regard (for a more comprehensive description see also Buysse, in press). Table 1 reflects efforts undertaken by NPDCI to summarize the most promising or effective practices related to access, participation, and supports within inclusion.

### Access

Access means providing a wide range of activities and environments for every child, removing physical or structural barriers, and offering multiple ways to promote learning and development. Access will mean something different for each child. For example, the first step in promoting the social development of a young child with developmental delays who has no or limited opportunities to play with typically developing peers would be to create such opportunities (e.g., by arranging play dates or enrolling the child in an inclusive early childhood program), prior to intervening using a social skills curriculum. For a child with significant communication delays who is already enrolled in an inclusive classroom, access would mean ensuring that this child has a way to communicate her wants and needs to primary caregivers, teachers, and other children (e.g., using sign language or a communication device). The joint position

**Table 1. Practices and Activities That Promote Access, Participation, and Supports**

Defining Feature of Inclusion	Instructional/Intervention Practices or Activities	Description
<p><b>Access:</b> removing physical barriers, providing a wide range of activities and environments, and making necessary adaptations to create opportunities for optimal development and learning for individual children</p>	<p>Universal Design (UD)/Universal Design for Learning (UDL)</p>	<ul style="list-style-type: none"> <li>• Supports access to early care and education environments through the removal of physical and structural barriers (UD)</li> <li>• Provides multiple and varied formats for instruction and learning (UDL)</li> </ul>
	<p>Assistive technology (AT)</p>	<ul style="list-style-type: none"> <li>• Involves a range of strategies to promote a child's access to learning opportunities, from making simple changes to the environment and materials to helping a child use special equipment and technology</li> </ul>
<p><b>Participation:</b> using a range of instructional and intervention approaches to promote engagement in play and learning activities, and a sense of belonging for each child</p>	<p>Embedded instruction/interventions (related terms include: routines-based or activity-based instruction/interventions and integrated therapy)</p>	<ul style="list-style-type: none"> <li>• Strategies that address specific developmental or learning goals within the context of everyday activities, routines, and transitions at home, at school, or in the community</li> </ul>
	<p>Scaffolding strategies:</p>	<p>Providing the following types of strategies across a wide range of teaching and learning contexts for children who require intensive learning supports:</p> <ul style="list-style-type: none"> <li>• Modeling: demonstrating how to do something</li> <li>• Response prompting: providing assistance to elicit a response</li> <li>• Variations of prompting and modeling: increasing/decreasing the level of assistance, adding wait time, or combining strategies</li> <li>• Peer supports: enlisting peers to support another child in learning</li> <li>• Corrective feedback: responses that reinforce correct responses and address incorrect responses or non-responses</li> </ul>
	<p>Tiered models of instruction/intervention</p>	<ul style="list-style-type: none"> <li>• Involves gathering assessments on children's behavior or learning to plan and organize instruction/interventions and to monitor progress.</li> </ul>
<p><b>Supports:</b> creating an infrastructure of systems-level supports for implementing high-quality inclusion.</p>	<p>Professional development</p>	<ul style="list-style-type: none"> <li>• Teaching and learning activities designed to support the acquisition of professional knowledge, skills, and dispositions related to inclusion as well as the application of this knowledge in practice. The content of the professional development should include evidence-based practices that define high-quality early childhood inclusion.</li> </ul>
	<p>Models of collaboration, communication, &amp; coordination</p>	<ul style="list-style-type: none"> <li>• Approaches that promote multiple opportunities for collaboration among key stakeholders (e.g., families, practitioners, specialists, administrators) to support implementation of high-quality inclusive practices. Models that support this type of collaboration include: technical assistance, consultation, coaching, mentoring, Individualized Education Program/Individualized Family Service Plan teams, collaborative problem-solving, and communities of practice/professional learning communities</li> </ul>
	<p>Policies</p>	<ul style="list-style-type: none"> <li>• Quality frameworks (e.g., early learning standards, professional competencies, program standards, quality rating and improvement systems) that reflect and guide high-quality inclusive practices as well as addressing the needs of the general population of young children and families.</li> </ul>
	<p>Resources</p>	<ul style="list-style-type: none"> <li>• Funding approaches that support the appropriation of resources across health and human service agencies and the strategic use of financial incentives to increase universal access to high-quality inclusive opportunities</li> </ul>
	<p>Research and program evaluation</p>	<ul style="list-style-type: none"> <li>• Research and program evaluation that advance knowledge and understanding about the most effective ways of implementing inclusion, develop and evaluate research-based practices that promote children's development and learning and family support, and identify strategies for improving the quality of inclusive services for children and families</li> </ul>

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statement (DEC/NAEYC, 2009) identified Universal Design (UD), Universal Design for Learning (UDL), and assistive technology (AT) as promising or effective practices for promoting access to inclusion.

**UD and UDL.** UD is a concept that means supporting the access of children with disabilities to many different types of environments and settings through the removal of physical and structural barriers, whereas UDL reflects practices that provide multiple and varied formats to promote wider access to teaching and learning activities (DEC/NAEYC, 2009). In 2007, DEC identified three essential principles of UDL in this regard: (a) multiple means of representation (i.e., learning opportunities provided in various formats and at different levels of complexity to address a range of ability levels and learning characteristics), (b) multiple means of engagement (i.e., using a range of strategies for arousing and maintaining children's attention, curiosity, and motivation in learning), and (c) multiple means of expression (i.e., providing a variety of options and formats for children to

respond, demonstrate what they know, and express their ideas and feelings). At this time, UD practices represent a promising but, as yet, unproven approach for promoting access within inclusion. Additional research is needed to determine the target population for whom these practices will be most effective and most feasible, the types of settings and contexts in which these practices work best, the professional development required to ensure that practitioners can implement these practices appropriately and with fidelity, and the benefits of using these strategies with young children and families.

**AT.** Project Connect (the Center to Mobilize Early Childhood Knowledge) developed a module on AT that offered the following definition: "AT interventions involve a range of strategies to promote a child's access to learning opportunities, from making simple changes to the environment and materials to helping a child use special equipment and technology" (Pierce, Lindauer, & Epstein, 2011). Adaptations and devices that are easy to find and use are considered low-tech because they include items such as bath seats and other baby equipment that are readily available at low cost to most families. At the other end of the continuum are specialized, high-tech devices that are more complex and include augmentative communication, switches, power wheelchairs, and computerized toys not readily available for use by the general population. A list of AT resources and related Web sites appears in the Learn More box. A research synthesis reviewed 104 articles on the use of AT with infants and young children (Campbell, Milbourne, Dugan, & Wilcox, 2006). The study found relatively strong evidence that children as young as 1 year old with various types of physical disabilities and developmental delays could be taught to operate switches to activate toys and devices, but also concluded that future research should shift from evaluating performance of isolated skills to promoting children's successful participation within the context of everyday activities and routines.

### **Participation**

Ensuring that environments and programs provide each child with access to learning opportunities does not guarantee that every child will be able to participate fully in those learning opportunities. For example, removing physical barriers and providing a communication device may promote access to learning for a child with cerebral palsy, but this child almost certainly will need additional individualized accommodations and supports to participate fully in play and learning activities with

peers and adults. Participation means using a range of instructional and intervention approaches to promote engagement, in both play and learning activities, and a sense of belonging for each child. The DEC/NAEYC (2009) joint position statement identified practices such as embedded interventions, scaffolding, and tiered models of instruction and intervention as promising or effective for promoting the participation of children with and without disabilities within inclusive settings.

**Embedded instruction and interventions.** Embedded instruction and interventions—and related practices such as embedded learning opportunities, routines-based intervention, activity-based instruction and intervention, and integrated therapy—embody the idea of supporting a child's development and learning (regardless of ability level) within the context of the natural environment. Embedded instruction and interventions are implemented in different ways and across different contexts, depending on the age of the child targeted for these services. For infants and toddlers with disabilities who receive Part C early intervention services, the most common location for such services is the child's own home, with a smaller number of children receiving services in a group-care setting. The embedded learning for infants and toddlers within a home-visiting context is commonly referred to as routines-based intervention and takes the form of supporting families in helping their children learn throughout the day, rather than working directly with the child with materials the home visitor introduces as parents observe (McWilliam, 2010). Most pre-kindergarten children (3- to 5-year-olds) with disabilities receive special education services in center-based early childhood programs or home-based child care settings. Embedded interventions can occur naturally anytime and anyplace; they build on children's interests; and they extend learning by offering multiple opportunities to practice new skills. A research synthesis of 38 studies (Snyder, Hemmeter, Sandall, & McLean, 2007) summarized by the Connect Project showed that children 2-7 years old with disabilities who received embedded interventions acquired targeted skills or made progress across a number of areas that included language and communication, motor and adaptive skills, cognitive development, academic learning, and social-emotional development (Winton, Buysse, Turnbull, Rous, & Hollingsworth, 2010).

**Scaffolding strategies.** Scaffolding strategies are structured, targeted approaches that practitioners, families, and specialists can use with children who require

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more intensive supports across a wide variety of teaching and learning contexts, and in combination with other approaches (e.g., as part of embedded interventions and tiered models). The research literature is replete with information on the effectiveness of different types of scaffolding strategies and various combinations and hybrids of these for use with infants and preschoolers with disabilities (Chiara, Schuster, Bell, & Wolery, 1995; Craig-Unkefer & Kaiser, 2002; Gibson & Schuster, 1992; Girolametto, Weitzman, & Greenberg, 2004; Hancock & Kaiser, 2006; Hawkings & Schuster, 2007; Kaizer, Hemmeter, & Ostrosky, 1996; Kaiser, Hester, & McDuffie, 2001; Kouri, 2005; Ostrosky & Kaiser, 1995; Ross & Greer, 2003; Walker, 2008; Wolery, 2000). All of these individual scaffolding strategies can be organized under several broad categories to create a more practical framework for applying these approaches to promote children's participation within inclusion. These categories include modeling, response prompting, variations of modeling and prompting, peer supports, and corrective feedback. Table 1 provides a description of each of these scaffolding strategies.

**Tiered models of instruction and intervention.** Tiered instructional approaches in early childhood are based largely on response to intervention (RTI), an approach that is gaining widespread acceptance in public schools throughout the U.S. for use in kindergarten through 12th grade. The key features of school-age RTI models involve (a) gathering information on students' skills to plan and organize instruction and targeted interventions and (b) monitoring progress in learning to support data-based decision-making. Although there is mounting evidence that RTI is an effective practice for improving reading and math skills for school-age children (Burns, Appleton, & Stehouwer, 2005; Gersten et al., 2008, 2009), RTI is generally considered an emerging practice when it is implemented prior to kindergarten. Across several widely implemented tiered models in early childhood, the primary emphasis is on helping practitioners (e.g., general early educators and specialists) organize the way in which they gather information and deliver instruction and targeted interventions to respond effectively to children's learning and social-emotional needs (Buysse & Peisner-Feinberg, 2010; Fox, Dunlap, Hemmeter, Joseph, & Strain, 2003; Hemmeter, Ostrosky, & Fox, 2006; *NHSA Dialog*, 2009a, 2009b; Peisner-Feinberg, Buysse, Benshoff, & Soukakou, in press; Sandall & Schwartz, 2008; Walker et al., 1997, 2008).



PHOTO: MARLEEN NOIR

**Routines-based intervention supports families in helping their children learn throughout the day.**

### Supports

As defined within the DEC/NAEYC (2009) joint position statement on inclusion, supports refer to broader aspects of the infrastructure or system that must be in place to undergird the efforts of individuals and organizations providing inclusive services to children and families. Examples of such systems-level supports would include ongoing professional development, collaboration and coordination among key stakeholders, public policy, resources, and research and evaluation. Table 1 briefly describes how each of these system components could serve as a support to high-quality inclusion.

### Conclusion

**T**HIS ARTICLE DESCRIBED CURRENT knowledge about early childhood inclusion, summarizing research and the DEC/NAEYC joint position statement on inclusion. The article also outlined effective or promising educational practices that promote access, participation, and supports—the defining features of high-quality inclusion. In the future, efforts to improve the quality of inclusion must begin to connect research-based practices such as AT or embedded interventions with the systems-level supports related to the broader program quality movement. These efforts should address, for example, quality rating and improvement systems, early learning standards, measurement and accountability, and professional development. Otherwise,

inclusion will continue to exist as a separate service delivery system apart from programs and services designed for the general population of young children and families. One area that seems ripe for developing these connections is the movement underway to customize teaching and learning to address the needs of an increasingly diverse population of young children and families (Buysse & Wesley, 2010). Just as in the broader field of K-12 education, there is a growing realization in early childhood of the need to customize teaching and learning to ensure that practitioners are equipped to help every child—including those with identified disabilities, those at risk for learning or behavioral difficulties, and those from diverse cultural and linguistic backgrounds—reach his full potential. If the field moves in this direction, perhaps one day Christine, the blogger quoted at the beginning of this article, will post a more hopeful message about her son's ability to participate fully in all learning activities and form meaningful relationships with his classmates and teachers. ♡

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**VIRGINIA BUYSSE, PhD**, is a senior scientist at the FPG Child Development Center at the University of North Carolina at Chapel Hill. She directs a program of research on Recognition & Response, a model of Response to Intervention for early childhood. Other research interests included early childhood inclusion, professional development, and educational practices for dual language learners.

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# Early Head Start and Early Intervention

*Partnerships That Make a Difference for Young Children With Disabilities and Their Families*

LINDA BREKKEN

*SpecialQuest Consulting Group  
Rohnert Park, California*

The partnership between Early Head Start (EHS) and Part C early intervention (EI) addresses an urgent need—the development of the youngest, most vulnerable children. EHS and EI are often the first point of contact for many families with infants and toddlers who are at risk or who have disabilities and are natural partners in serving these vulnerable families. EHS offers EI programs inclusive natural environments for service provision and EI provides EHS programs with support to include infants and toddlers with disabilities in 10% of EHS enrollment, as mandated by law. The two programs can augment one another's services with key ingredients to successful intervention and support for infants and toddlers with disabilities and their families.

This article outlines the relationship between the two programs and shares the evaluation findings and experiences from the work of the Hilton/Early Head Start Training Program and the SpecialQuest Birth-Five: Head Start/Hilton Foundation Training Program (SpecialQuest), a public-private partnership between the Conrad N. Hilton Foundation and the Office of Head Start. SpecialQuest worked with more than 500 EHS and EI programs throughout the United States between 1997 and 2010. This article highlights information about successes, challenges, and lessons learned in providing collaborative inclusive EI services in EHS programs (Brekken & Corso, 2009; Corso, Pickard, Brekken, Bernheimer, 2007; Corso, Pickard, Brekken, Bernheimer, 2010).

## The Context for EHS and EI Partnerships

THIS IS AN exciting time for early childhood services. Research shows many benefits of providing services to infants and toddlers at risk and with disabilities and their families (National Research Council & Institute of Medicine, 2000). As a result, legislation, policies, and funding have expanded services to these populations. Since 1987, EI services to infants and toddlers with disabilities and their families have been mandated through Part C of the Individuals With Disabilities Education Act (IDEA, 2004). Services to infants and toddlers at risk have also been viewed as an important investment in our nation's future (Heckman, 2010; Rolnick & Grunewald, 2003). An increasing number

of supports have been provided to infants, toddlers, and their families, including services through EHS programs which began in 1994. Recently, EHS has been expanded

### Abstract

A coordinated, comprehensive approach to early intervention has the potential to promote optimal development and create a brighter future for young children at risk or with disabilities and their families living in poverty. This article outlines the relationship between Early Head Start (EHS) and early intervention (EI) in the areas of child find, individualized planning and service delivery, family support, transition, and community partnerships. Evaluation findings and recommendations from the SpecialQuest work with more than 500 EHS and EI programs throughout the United States between 1997 and 2010 highlight the importance of relationship building between programs, shared learning opportunities, a shared vision, family and community engagement, time for collaboration, administrative support, and continuous improvement.



through American Recovery and Reinvestment Act (2009) stimulus funding to address the impact of rising rates of children living in poverty. Current data indicate 46% of children from birth to 3 years old are living in low-income households and 26% are living in poverty (Chau, Thampi, & Wight, 2010).

Early childhood inclusion, or the practice of serving children in settings with their typically developing peers, has received a great deal of attention from research findings (Guralnick, 2001; National Professional Development Center on Inclusion, 2007), policy, and recommended practice (Copple & Bredekamp, 2009; Division for Early Childhood /National Association for the Education of Young Children, 2009; Sandall & Ostrosky, 2000; Sandall, Hemmeter, McLean, & Smith, 2004). In addition, federal policies are emphasizing a coordination of efforts across all early childhood programs in the U. S. Departments of Education and Health and Human Services to increase the effectiveness of the services and to reduce duplication of services.

### ***Shared Eligibilities***

EHS programs are designed to provide comprehensive services to pregnant women and to families living in poverty who have infants and toddlers. EHS programs are required to serve children with disabilities as at least 10% of their enrollment. Head Start Performance Standards define children with disabilities as children who are eligible for EI services in their state and who have a Part C (IDEA) Individualized Family Service Plan (IFSP). Because of the impact of poverty and other risk factors, EHS programs are likely to identify and serve a significant number of children with disabilities. In fact, more than 40% of the children with disabilities participating in Head Start are identified while they are enrolled in EHS (U.S. Department of Health and Human Services, 2010). In 2009–2010, EHS and Migrant and Seasonal Head Start served more than 120,000 infants and toddlers and their families in more than 1,000 EHS programs across the country (U.S. Department of Health and Human Services) and of that number, 11.9% or 14,289 were identified as infants and toddlers with disabilities.

EI programs served 342,985 infants and toddlers with disabilities and their families in 2008. According to the most recent data from the Office of Special Education Programs approximately 2.66% of the overall population of infants and toddlers received EI services (Danaher, Goode, & Lazara, 2010; U.S. Department of Education, 2009). EI programs are required to serve infants and toddlers with disabilities in natural environments. That is, services are provided where children without disabilities typically spend their



PHOTOGRAPHER: GARY CHRISTIAN FILM AND VIDEO. PHOTO COURTESY OF THE SPECIALQUEST CONSULTING GROUP

**EHS programs are required to serve children with disabilities as at least 10% of their enrollment.**

time—this includes the child’s home, as well as child care, EHS, and other early childhood settings. Because EHS is required to serve infants and toddlers with disabilities and also has an infrastructure that enables programs to provide comprehensive services and collaborate with community partners, they are often an ideal option for serving infants and toddlers with disabilities in natural environments. However, although EHS programs are located in every state in the U.S., they are small programs and not universally available. Thus, EHS programs are currently serving less than 4% of the eligible population.

Participation in EHS increases the likelihood of a child receiving EI services. Findings from the EHS National Research and Evaluation Study (U.S. Department of Health and Human Services, 2006) show that infants and toddlers served by EHS were significantly more likely to receive EI services than control group children. This may be due to the screening and referral processes and the relationships with the Part C providers. The study also revealed gaps between the need for and the receipt of Part C services—especially by families who were less well-educated, teen parents, Hispanic families, and families with multiple risk factors. The National EI Longitudinal Study found that the families who had the most difficulty accessing EI services were those who had multiple risk factors, particularly low income families from diverse cultural and linguistic backgrounds—a population similar to the families served by EHS (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004).

### ***Shared Legislative Intent***

Having similar mandates and philosophies is not enough. Despite having mandates for inclusive services and supports, both EHS and EI face challenges in creating a supportive and inclusive climate for infants and toddlers with disabilities. Administrative support and staff training—in both programs—are necessary. EHS staff need to understand the importance of their role with children who have disabilities, be comfortable and confident in serving infants and toddlers with disabilities in their programs, and have skills and supports to address the child’s and family’s special needs. EI staff need to feel comfortable referring children to, and integrating their services with, EHS programs. Creating this climate of mutual respect and appreciation requires an intentional process of exploring what each program has to offer and how they can support each other’s efforts. Families need the services, and they need these services to be supportive and well-coordinated.

EHS programs have worked with their Part C EI partners across the country to collaboratively serve infants and toddlers with disabilities and their families since the inception of EHS in 1994. Through the visionary efforts of the Hilton Foundation and the Head Start Bureau, SpecialQuest brought together more than 500 EHS programs, families, and EI partners to learn together and from one another, develop and implement plans to enhance inclusion in their communities, and assess their progress and make modifications to ensure that



**Both EHS and EI have a family-centered approach and philosophy and are responsive to the family's language and culture.**

children and families received collaborative and coordinated services. These programs and families provided a rich source of information on how programs have worked together to support inclusion of infants and toddlers with disabilities and their families within the context of their communities.

The evaluation data from SpecialQuest focused on the impact of the intensive, team-based training with follow-up over time and showed a strong positive impact on participating programs (Brekken, 2004; Corso et al., 2007, 2010). EHS programs and their EI partners increased the number of infants and toddlers with disabilities served in EHS, served more children with more significant disabilities, increased staff comfort and confidence in serving infants and toddlers with disabilities, provided more services to families, developed family leaders, increased reciprocal referrals between EHS and EI, provided more coordinated services, and developed strong collaborative relationships. Program case studies, on-site observations and interviews, focus groups, and other data document the points of intersection, challenges, and effective strategies for collaborative inclusive services in the areas of child find, individualized planning and service delivery, family support, transition, and community partnerships. Each of these elements of services are described in the following sections with examples and strategies for coordinated inclusive services for young children with disabilities and their families jointly served by EHS and EI.

### *Joint Responsibility for Early Identification*

Both EHS and EI, along with other agencies, have the responsibility for child find—a process for the early identification of children with disabilities and ensuring that children and families get needed services as early as possible in the child's life. EI and EHS are required to work with hospitals, pediatricians, EI programs, and other community partners to recruit and enroll infants and toddlers with disabilities, as well as to have policies and procedures in place to ensure that as they identify children in their programs who might need Part C services they can refer families to additional services.

In many communities, EHS and EI have coordinated their child find efforts and systems. Some communities have conducted community-wide health and developmental screening fairs. In other communities EI staff screen all children in EHS and child care. Several communities have worked together and trained all their staff so that they use the same screening and assessment tools. In all of these situations, it is critical to make sure that everyone in the community knows what to do if they have concerns about a child's development and establish clear guidelines for referral processes.

In communities where there are strong partnerships, the referrals between agencies are more frequent and more appropriate. In addition, programs noted that children who might have gone undiagnosed in the past are identified and served earlier when EI and EHS child find efforts are coordinated. EHS is seen

as an important part of the early identification and intervention system. Communities have also set up common referral forms and established interagency referral teams that meet regularly to discuss and address new referrals. As EHS and EI programs worked together and better understood each other's systems, they significantly increased the rates of reciprocal referral.

### *Individualized Planning*

Both EHS and EI are based on individualized services for children and families. EI requires an IFSP process that outlines services that the child and family need; intended outcomes of these services; and how, when, and by whom the services will be provided. EHS has requirements for individualized services for all infants and toddlers, including the support for implementation of the IFSP. EHS programs also have a requirement that the Family Partnership Agreements are developed and coordinated with child or family plans developed through other service providers, such as the IFSP, or with child welfare if the family is involved with child protection or foster care.

A key step in the initial IFSP process is a series of observations, assessments, and evaluations that lead to identification of a disability. Staff from all agencies involved in the identification process need to work together to ensure that all individuals understand the processes and roles involved in identification and in preparing families to participate in the development of the IFSP.

Some of the challenges encountered by EHS and their EI partners relate to involvement of EHS in the process of developing the IFSP. In order for EHS to assist in meeting the outcomes of the IFSP for children that they serve, it is important that they are involved in developing the IFSP, have copies of the document, and know how they can implement strategies in their home visits and group activities.

SpecialQuest evaluation results indicated that when EHS staff were involved throughout the IFSP process, they were able to share their observations of children's strengths and needs, identify priority areas for services, and contribute to an IFSP that reflected the perspectives of families, EHS, and other service providers working with the family, as well as the specialized expertise of the EI providers. Joint training was conducted to clarify procedures to ensure that families and EHS staff understood the IFSP process and how to fully participate in planning and implementing the IFSP. In many communities EHS staff were instrumental in encouraging and supporting families who might be reluctant to access needed EI services. EHS

served as important support for families as they moved through the IFSP process. Interagency agreements were developed to ensure that these collaborative procedures were clarified and shared with all staff who would need to implement them.

### **Individualizing and Coordinating Intervention Services**

Individualized services require a foundation of developmentally appropriate practices for all children that address children's temperament, learning styles, and preferences. Many EHS staff have a strong background in child development and receive ongoing training in developmentally appropriate practices but do not have extensive experience and background in specialized services often needed to maximize the potential of the child who has a delay or disability. EHS home visitors or center-based teachers work most effectively with infants and toddlers with disabilities and their families when they have support and work as a team with EI providers to embed IFSP outcomes into ongoing curriculum and integrate therapy strategies into joint home visits or within group settings.

Some of the challenges identified by SpecialQuest community teams included communication among all parties, including families; coordinating services when there were differences in service delivery models (home, center-based, or community-based); providing EI services and supports in the context of the classroom; difficulties in finding qualified therapists; and staff turnover resulting in a lack of or discontinuity of services.

EHS programs that participated in the SpecialQuest training significantly increased the number of children with disabilities who were served and the number of children with significant disabilities who were served. EHS and EI staff reported that they increased their skills significantly in working with infants and toddlers with disabilities and their families. They reported increased skills in implementing inclusive, integrated services, as well as integrating the IFSP outcomes into their home visit or center-based learning environments.

Participants provided many examples of effective strategies to coordinate service delivery in their communities. One key strategy was shared professional development opportunities so that staff from all systems benefit and learn together. Ongoing communication and consultation processes ensured that everyone working with the child and family were working toward common outcomes. Collaborative services require adequate time for joint planning, as well as strong administrative support.



PHOTO COURTESY OF THE SPECIALQUEST CONSULTING GROUP

**Participants in SpecialQuest training reported that they significantly increased their skills in working with infants and toddlers with disabilities and their families.**

Depending on the service delivery models in the community, staff may conduct joint home visits, or provide EI services that are embedded as part of the EHS or child care daily routines. Ensuring that families are a part of the collaborative service delivery systems is also an important consideration. In many communities a communication log is completed—for center-based programs, the log is kept in the classroom and sent back and forth between home and center with the child. In home-based programs families may keep a home visit log, where all of the service providers record notes on services provided and progress toward the desired outcomes.

### **Shared Values for Family Support**

Both EHS and EI have a family-centered approach and philosophy. EHS is required to assist families in understanding services, engaging them in services, and encouraging them to be advocates for their child. Services should also be responsive to the family's language and culture. EHS and EI providers support families in learning about their child's disabilities, advocating for needed services, and making informed choices. It is impossible and unrealistic to expect that a single service provider will have all the requisite knowledge, experience, and expertise to meet the needs of families who are living in poverty, experiencing multiple risk factors, and dealing with the added impact of a child with disabilities. Thus, both systems emphasize the importance of coordinating supports for families. EI has a role of service coordinator, and EHS has a number of roles to provide such support, including the home visitors, family service workers, and disabilities coordinators.

The families that EHS and EI jointly serve are families with multiple needs necessitating coordination of a variety of different services.

EHS needs EI to provide the specialized support to address the child's disability and help the family to follow through and implement recommendations in the home. EI needs EHS to help address the complex needs of these families, such as accessing health, mental health, food, housing, job training, or parenting education.

Families in EHS are often working or attending school to further their education. EHS helps families identify quality child care services if they do not directly provide such services. EI providers often assume that the natural environment is the home. Part C data indicates that the home was the primary EI service setting for 86% of the families receiving EI in this country. If families are working or going to school, as most low income parents are, this may not be the most convenient service delivery model, as this family shared:

*My big thing was getting [early intervention] inside the day care. I was taking him to [therapy] outside of day care, but that was killing me in the morning. So I was trying to get this set up in the day care center so I didn't have to do all this running around, and so the physical therapist would come to my child and work with him, and then I wouldn't have to worry about taking off work and threatening my job.*

EHS and EI programs shared a number of collaborative strategies that helped families access information, resources, and support. Programs worked together to contribute their expertise to support families as informed decision makers and advocates for their children. For example, EHS might provide bilingual, bicultural staff to support families who were non-English speaking in partnership with EI. EHS staff might transport families to appointments with specialists and



Head Start requires programs to develop interagency agreements so that the roles and responsibilities of the respective programs are clarified. Both systems have roles and supports to bring community resources together to meet the needs of families. The quote below is an example of what all families should experience:

*I've had a wonderful service coordinator through [the EI program] . . . she had all the services set up. Our EHS has just started this past year—the timing was absolutely perfect—and I wouldn't have even known about the program. She's the one that went ahead and said, "They're just going to open in July,"—that's when I needed it, and it was just all there for me. She coordinated all my therapists to come in to the school, because I work in the county, and I can be there for each service provider, each therapist, so that they can train me at the same time as they're teaching the staff and working with my child. So I've had an excellent experience.*

There are close parallels between the two programs that facilitate collaborative service delivery. However, each program is unique and differences in state regulations, program procedures, and policies must also be taken into account. The guidance for the “what” of services is relatively clear. The “how” of collaborative service provision is a critical and sometimes overlooked issue. The bottom line is that each partner needs to know the rules of the game in order to play together. Making sure that everyone involved, especially families, understands the rules, roles, and responsibilities of the team of service providers can greatly enhance the effectiveness of services. One program administrator commented:

*It has changed the way the community views our EHS program and their involvement in EHS, and it has changed our view with the families we serve. We don't provide just child care we provide “family care.” Our collaboration with our partners has opened doors of communication that together we provide continuity of care to children and families and a higher quality of services. Medical providers are supporting our efforts to provide high quality services to families of children with disabilities.*

### **Building Collaborative Inclusive Services**

**T**HE EXPERIENCES OF EHS and EI programs working together to provide inclusive services for infants and toddlers with disabilities and their families have provided a number of lessons learned.

### **EHS offers an inclusive “natural environment” for service provision.**

ensure that families understood information by clarifying any questions or concerns.

Families that participated in SpecialQuest also reported an impact on their leadership skills and their ability to advocate for their children. The impact of having a family member on the team also provided a new perspective for many professionals, as one shared:

*Having families involved keeps the team grounded and reminds us of the reasons for this work. It also gives the team feedback on what's really working for families and their children.*

An important aspect of family support is helping families to feel a part of their community, reducing the isolation and stress on families. Families also expressed how important it was to see their child with a disability learning with other children and for their children to be part of the group and have friends.

### **Transition Planning**

EHS and EI each have requirements for transition planning from infant-toddler services to preschool services. EHS is required to begin transition planning at least 6 months prior to when the child turns 3 years old. EI programs are required to conduct transition meetings no later than 90 days and no earlier than 9 months before the child's third birthday. Although the programs have complementary provisions, these slight differences in timelines need to be coordinated.

EHS and EI programs developed a variety of strategies to address the complexities of transitions in their communities. Evaluation results indicate that one key was to clarify transition procedures in interagency agreements or transition plans. Ongoing communication, joint training, and coordinated planning resulted in a number of communities developing transition guides for families and transition teams to facilitate the process. Helping families understand and prepare for the transition process was a major part of their collaborative activities.

### **Linking With Other Resources**

Both EHS and EI systems expect that individual service providers coordinate with other community partners to benefit the children and families that they jointly serve.

### **Learn More**

The following Web sites provide a variety of resources and information pertaining to Head Start/Early Head Start and Early Intervention for children with special needs.

**HEAD START CENTER FOR INCLUSION**  
[www.headstartinclusion.org](http://www.headstartinclusion.org)

**EARLY HEAD START NATIONAL RESOURCE CENTER**  
[www.ehsnrc.org](http://www.ehsnrc.org)

**NATIONAL EARLY CHILDHOOD TECHNICAL ASSISTANCE CENTER**  
[www.NECTAC.org](http://www.NECTAC.org)

**NATIONAL EARLY CHILDHOOD TRANSITION CENTER**  
[www.IHDI.uky.edu/nectc](http://www.IHDI.uky.edu/nectc)

**NATIONAL PROFESSIONAL DEVELOPMENT CENTER ON INCLUSION**  
[www.fpg.unc.edu/-NPDICI](http://www.fpg.unc.edu/-NPDICI)

**SPECIALQUEST**  
[www.specialquest.org](http://www.specialquest.org)

## **Relationships Are Key**

EHS and EI partners forged strong relationships that were mutually supportive for the programs and for children and families. These relationships opened doors to collaborative services. Staff knew who and when to call and communicated with each other regularly. Partners were more willing to do something for people that they knew would also provide reciprocal support. As with any relationship, time must be spent building and maintaining it; it can't be taken for granted—or it may erode. One early childhood program director commented,

*SpecialQuest has allowed our staff to become better informed about the resources that are available in the community as well as build relationships with those partners. Better relationships spark better collaboration.*

## **Learn From and With Your Partners**

As programs began to work together they better understood each other's services, requirements, and systems. Similar to learning about children and families, the community partners shared information about their eligibility, referral processes, and service delivery and identified ways to work together. Learning together as a community team both through the SpecialQuest team experiences and through shared trainings for staff throughout the community created a common understanding. Another effective strategy was to do cross-system job shadowing (e.g., spending a day working side-by-side with staff in another agency) so that staff had an in-depth understanding of each other's roles and responsibilities.

Learning from the families that they served was also important. Teams that had strong family support and provided opportunities for family leadership in planning, service delivery, and professional development experiences shared that the family voice changed the way that they delivered services. Early childhood staff shared the importance of family leadership:

*Parents have made us aware of what they need and want for their child. They tell us how they feel about services they receive and what it is like to be on the receiving end. We are able to develop better plans for children with parent input.*

## **Develop a Shared Community Vision for Inclusion**

Community teams found that developing a shared vision for inclusion helped to focus

their work and solidify their commitment to inclusion. The vision was used to guide their work, to communicate their shared vision with others, and as a unifying force in their coordinated services for all children, as illustrated in this comment:

*Making sure it's not a second thought, that we're including all children, and we didn't have to say "and including children with disabilities."*

## **Make Time for Collaboration**

Building collaborative relationships and systems takes time. EHS and EI were most successful in providing collaborative, inclusive services when they intentionally built in time for joint planning and for opportunities to work together. They found that establishing regularly scheduled times for meetings and communication and linking collaborative activities to their ongoing responsibilities helped facilitate strong partnerships—so it did not feel like merely one more task. A state administrator shared,

*One of the key things is to figure out how collaboration is embedded within your current work and not seen as something "in addition to."*

## **Actively Involve Community Partners and Families**

EHS, EI, and their partners found it important to engage everyone involved in planning, developing, and carrying out action plans and specifying roles and responsibilities, timelines, and intended outcomes. The buy-in for inclusion has grown as the groups accomplished goals and celebrated their success. The following quote illustrates the positive impacts of collaboration:

*Aspects of the community has been beneficial. It's good for all members of the community to hear how collaboration really works and has benefited so many children and their families.*

## **Gain Administrative Support**

Administrative support affects all aspects of inclusive services. Administrators who value inclusion and support collaboration create an organizational climate of respect and belonging for all children and their families. Communicating these values through hiring practices, budget and resource allocation, training, and support for inclusion within the program, as well as with community partners, is critical. In working across systems such as EHS and

EI, administrative support in all agencies is essential for effective partnerships and interagency agreements.

## **Continually Review and Refine the Work**

Successful collaborations between EHS and EI programs included opportunities for reflection on their work with children and families and identified areas that needed to improve. They engaged in reviewing data and joint problem solving, exploring a variety of options for delivering high quality inclusive services. Their work was characterized by an openness to identifying challenges, trying new ideas and practices, and having a sense of accountability—to each other and to children and families. This process of continuous improvement also created a climate of trust among team members as they followed through on their commitments, thus enhancing relationships that are the foundation for effective inclusion.

## **Conclusion**

**E**HS and EI are natural partners in serving infants and toddlers with disabilities and their families living in poverty. The two programs have complementary purposes, regulations, philosophies, and requirements. They cannot effectively serve children with disabilities in isolation. The programs provide a lifeline of important supports—if they work together with each other, with families, and with other community partners, they can maximize the impact and create a bright future for the many families who need us! §

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**LINDA BREKKEN, PhD**, is the director of the SpecialQuest Consulting Group at the Napa County Office of Education, building on many years of work to promote inclusive services for young children with disabilities and their families in communities and states across the country. Dr. Brekken and her team designed and developed the award-winning SpecialQuest videos and training materials (The SpecialQuest Multimedia Training Library) that have been shown to be effective and innovative ways of providing professional development and creating change for early childhood inclusion. She has designed, directed, and evaluated many innovative state, regional, and national training and technical assistance programs which focus on improving services to infants and preschoolers at risk or with disabilities and their families since 1980.

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[www.zerotothree.org/developmentassessment](http://www.zerotothree.org/developmentassessment)

A developmental assessment is a process designed to deepen understanding both of a child's competencies and resources and of the caregiving and learning environments most likely to help the child make fullest use of her developmental potential. Learn about eight tips for parents preparing for the developmental assessment of their child.

### Questions and Answers About Early Development

[www.zerotothree.org/readinessqna](http://www.zerotothree.org/readinessqna)

Read commonly asked questions and find resources to help support early development in babies and toddlers.

### Promoting Early Language and Literacy Development

[www.zerotothree.org](http://www.zerotothree.org)

ZERO TO THREE's Policy Center announces the release of a video and a new policy brief illustrating how early language and literacy development contributes to a child's success throughout life. The video is currently located on our home page. You can play the video right from our site to show it to policymakers, advocates, community partners, and others. And be sure to check out the early literacy webinar and our wealth of early literacy resources, also currently located on the home page.

# Sustaining Family Involvement in Part C Policy and Services

## *Successes and Challenges Moving Forward*

MARK A. SMITH  
DARLA GUNDLER  
MAUREEN CASEY  
TALINA JONES

*The Early Intervention Family Alliance  
Boston, Massachusetts*

The passage of the Education of the Handicapped Act (1986) mandated educational services for children with disabilities starting at age 3 years. It also included language promoting the implementation of an entirely new program under Part H of the Act, in which states that chose to participate would be eligible to receive federal funding and technical support to develop a comprehensive, multidisciplinary, statewide system of early intervention (EI) services to infants and toddlers with disabilities and their families. While some, albeit relatively few, states were already providing educational services to infants and toddlers with disabilities, Part H established the conditions (a) that these services be family-focused, (b) that states provide service coordination supports to families, (c) that states actively promote interagency collaboration among stakeholder state and local agencies, (d) that EI programs focus efforts on identifying all eligible children, and (e) that states establish State Interagency Coordinating Councils (ICCs) to oversee the implementation of these programs and to actively pursue the amelioration of systemic gaps and barriers to program implementation. Part H also included the unique requirement of parent participation in the implementation and oversight of these programs meaning that parent involvement was required in the new system. The state ICCs were required to include state agency stakeholders in their membership. In addition, at least 20% of the ICC membership was to consist of parents with young children with disabilities. While innovative, family involvement in the disability field in the United States had been key in advancing significant change to the field in the latter half of the twentieth century.

Prior to 1960, the common refrain that parents of newly identified children with disabilities would hear from the medical community was that “the best place for your child is...,” followed by a referral to the state or regional institution established for individuals with disabilities. Indeed, thousands of Americans with disabilities spent their entire lives in such settings. These institutions were

typically located in rural areas and removed from the view and general awareness of the community at large. The seminal event that began a national shift away from this policy was the election of John F. Kennedy as president in 1960. President Kennedy, while being a member of a prominent Northeastern family, a WWII war hero, and nascent politician, was also the sibling of a sister with

disabilities. In partnership with other members of his family, President Kennedy established the President’s Panel on Mental Retardation, the first national group to study disability in the United States. The Panel initiated a call to action to increase research, review public policy, and enhance the quality of practice regarding the care and support of individuals with disabilities. As a result, a national deinstitutionalization movement was launched.

### **Abstract**

**For thousands of parents of children with delays or disabilities, early intervention (EI) is the start of a lifetime of personal advocacy—learning to speak up on behalf of their own child to obtain the supports and educational experiences that establish future success in school and in life. Facing severe cuts in budgets, narrowing of eligibility criteria, and gaps between EI and preschool services, families all over the United States have moved beyond “telling their stories” to becoming vigorously engaged in policy and advocacy work at the state and federal levels. Parents can do what EI professionals cannot: bring the reality of “return on investment” to policy and advocacy for Part C of IDEA—the promise of EI. This article presents strategies for engaging families in policy work and examples of the efforts of successful parent advocacy.**



**Prior to 1960, thousands of Americans with disabilities spent their entire lives in institutions.**

President Kennedy, along with other members of the Kennedy family including his sister Eunice Kennedy Shriver, founder of Special Olympics, saw to it that more resources were devoted to move the locus of services for individuals with disabilities from institutions to their communities. At the same time, grassroots family movements such as the national and state Arc organizations began to question the status quo as it had stood for so many years. At the heart of this movement was questioning the practice of segregating individuals with disabilities; a national call by parents and professionals, in concert with national policymakers, resulted in a nationwide series of investigations of state institutions, which were routinely found to provide woefully substandard care, and in calls to close state institutions. The investigations led to lawsuits—*Willowbrook*, *Pennhurst*, *Alabama PARC*, *Partlow* (Trent, 1994) and many others—filed against states by family members across the country and the eventual closures of many public institutions. The deinstitutionalization movement continues to this day.

Given that children with disabilities were no longer removed from their families as the standard of practice, families were faced with the question: “What’s next for my child?” While community-based services were being developed in many areas to serve the needs of formerly institutionalized adults, there was little if any infrastructure to support the needs of children with disabilities and their families. Parent advocates, in partnership with legislators and policymakers, set about the task of ensuring the educational rights of children with disabilities. A 10-year period of parent advocacy and collaboration resulted in the passage of the Education of All Handicapped Children Act (1975), which established the rights of all children to a

free and appropriate public education based on the equal protection clause of the 14th Amendment. This Act included such key provisions as due process rights, Individualized Education Plans, and least restrictive environment. The question of “what’s next” was answered with the guarantee that children with developmental challenges had the same rights and access to public services, in this case educational services, as their typical peers. And, as had occurred in earlier shifts in the disabilities paradigm, families were to a great extent the “drivers” of the need for, design of, and implementation of change.

Families have stepped forward to shape the future in regard to disability and other special needs and continue to actively work to ensure systems of support which culminate in the best lives possible for all children. In each of the examples described below, family members moved beyond the role of advocating for their child or family member with a disability to advocating for systems and policy improvements at the local, state, and national levels.

### Family Representation on State Interagency EI Councils

**F**OLLOWING THE PASSAGE of the Education of the Handicapped Act (1986,) states began to develop statewide early intervention (EI) systems under Part H of the law, which included the establishment of ICCs in each state and territory. One of the many challenges states and territories faced in meeting the requirements of Part H was the requirement for parent participation in planning these new systems. Federally funded technical assistance was specifically targeted to each state’s designated Lead Agency, state ICC chairpersons, and state Service Coordination representative. Locating, including,

and orienting parent representatives were left to the state EI programs and ICCs. States and territories began to recruit parents to serve in these roles and continue to do so to this day. It was necessary along the way to develop practices to ensure that parent members were empowered to serve as equal participants in the implementation and ongoing oversight of state EI systems. For example, some of the newly formed Part H programs hired professional Parent Partners to assist in identifying family representatives and instituting practices—such as direct individual mentoring, pairing newer with more experienced family members, or conducting trainings—to support their participation. Program staff members in the Parent Partner role came from varied backgrounds, but typically were parents of children with special needs and were familiar with the requirements of new Part H. From 1986 until 2004, there was also a Federal Interagency Coordinating Council (FICC), 20% of whom were parent members, that served the same functions at the national level. *The Principles of Family Involvement* technical assistance document (Smith & Hansen, 1998; see box Principles of Family Involvement) was developed by the Family Empowerment subcommittee of the FICC and continues to provide a strong framework for engaging parents in state advisory councils and other policymaking groups.

As ICCs were developed, many groups argued for “a seat at the table.” By requiring that families have guaranteed representation, Congress ensured that there was the opportunity for equal expression of the experiences of families in EI systems. Families serving on ICCs share their experiences, and those of their peer constituents, along with other entities represented on the ICC. This sharing allows the membership the opportunity to learn about the challenges families face as well as those confronting municipalities, public and private providers, and state agencies in implementing EI services. By having each constituency at the table, the resulting policies are richer and more reflective of what happens in families and in the field at all levels.

### Moving From Child to Systems Advocacy

**M**ANY STATES PROVIDE families the opportunity to learn about the EI system in their state and their rights under the Individuals With Disabilities Education Act, (IDEA; 2004). It is important for families to understand the rights they and their child are afforded under the law so that they can make informed decisions as part of the Individualized Family Service Plan team. Under IDEA, families are equal partners with providers, evaluators, and local government representatives in determining the services



## PRINCIPLES OF FAMILY INVOLVEMENT

Developed by the Federal Interagency Coordinating Council (FICC) in 2000

### **Demonstrate family independence and contribution.**

- Develop a plan for identifying a diverse, representative group of families to participate.
- During and after meetings, specifically recognize the value of the family's participation.
- Recognize individual family strengths while respecting the different methods of coping and adjustment.<sup>1</sup>
- Demonstrate how Federal programs support families to attend national conferences.

### **Provide family-identified supports to assist the family's participation.**

- Provide convenient meeting times and locations for family members.
- Compensate families for their time, expertise, and expenses.
- Clearly identify a staff person to be the primary contact person for reimbursement and other issues.
- Be sure she/he understands that timely reimbursement and contacts are essential.
- Develop provisions that ensure that parents are present to participate in policy-related activities including direct staff support, stipends, travel expenses, and child care.
- Identify these supports in RFP's, grants, and policy.
- Provide complete, appropriate information prior to meetings in a timely manner.
- Match veteran parents with inexperienced family members to ensure that new members feel supported in their roles as advisors and have the opportunity to share their ideas.
- Consider incorporating a "family leave" policy so family members can choose an inactive role but maintain their membership should family circumstances require some time off.
- Recognize that some family members may require more and different kinds of support than others to participate in a meaningful way.
- Encourage and facilitate family-to-family support and networking.<sup>2</sup>

### **Provide formal orientation for families and provide information for involving them.**

- Provide orientation to both family members and staff about the issues, participants, and process.
- Provide informational support for parents to be prepared to participate as equal partners on a "level playing field" with their professional counterparts.
- Provide technical assistance, leadership mentoring, training, and other parent leadership teaming.

### **Ensure diversity among family members.**

- Honor the racial, ethnic, cultural, and socioeconomic diversity of families.<sup>3</sup>
- Provide all materials in the families' preferred language.
- Recruit broadly from the community and the population the program serves.
- Bring in new families.
- Adapt collaborative models to diverse cultures. Manage changing distribution of power and responsibility. Incorporate principles of collaboration into professional education.<sup>4</sup>
- Ensure broad representation among parent groups based upon the community(s) in question.
- Be particularly careful to include members of traditionally underserved groups.
- Avoid any appearance of tokenism.

### **Be ready to hear what families say.**

- Encourage and support family members to find their voice.
- Ensure that parent perspectives are not considered a separate component of the policymaking process, but instead are infused throughout.
- Always consider an individual parent's story as being valid.

### **Respect the passion families have for change. Celebrate the partnerships of working together for change.**

- Support staff in developing an understanding of the value of family participation.
- Provide clear information about the goals of the board, task force, or committee and the role of individual members and the roles of family members.
- Balance membership on committees between families and professionals.
- Consider shared leadership—parent and professional co-chairs or teaming.

<sup>1</sup> Early Childhood Corner. (2000, Spring). *Principles of Family-Centered Care, Newsline, The Federation for Children with Special Needs.*

<sup>2</sup> Early Childhood Corner. (2000, Spring).

<sup>3</sup> Early Childhood Corner. (2000, Spring).

<sup>4</sup> Epstein, M., Kutash, K., & Duchnowski, A. (Eds.). (1998). *Outcomes for children and youth with behavioral and emotional disorders and their families* (pp. 233–234). Austin: PRO-ED.

Source: Smith & Hansen, 1998. Primarily adapted from Jeppson & Thomas (1995). *Essential Allies: Families as Advisors*. Bethesda, MD: Institute for Family-Centered Care.

and supports that are needed to address the developmental needs of their children. As families learn about their rights, they can be better advocates for their own child and family. States provide this information to families through a variety of means, including supporting the work of the local Parent Training and Information Center (federally funded through IDEA and available in every state), the use of Family Handbooks, which can provide an overview of the steps in the EI process, products documenting Procedural Safeguards in IDEA, individual discussions with service coordinators, on-line Webinars, and group workshops.

Many families transition their advocacy to other systems as their child transitions from EI. Children and families who leave EI continue to interact with many other early childhood systems, including preschool special education services, Head Start, Title V maternal and child health, medical systems, developmental disabilities, mental health, and others. The advocacy skills learned as part of the EI system help parents continue to advocate on behalf of their own child, other children and families, and on behalf of the EI system. In order to be successful advocates at the broader community or systems level, family leaders informed the field that they first need to process the fact that their child had a disability and what that would mean for their own child and family. They need to learn about the history of the disability movement and how that influences what is available for their child and family; and they need to connect with other parents of children with disabilities and adults with disabilities to learn of the breadth of the disability movement. Advocacy starts locally for families, with their own child and family, but with information, skills-development and support that can be transformed into advocacy on behalf of all young children with disabilities and their families.

## State Support for Parents in Policymaking

SOME STATES PROVIDE opportunities for families to attend trainings to learn how to become involved in policymaking decisions. These states provide funding and support staff to train groups of families on how to view the larger EI system and on how it is influenced by laws, regulations, and policies that are focused on the well-being of all infants and toddlers. There is a long history of parent leadership training to families and self-advocates in the developmental disabilities community (the following are just a few examples of these types of programs and are not intended as an exhaustive list.) For example, New York Developmental Disability Leadership training is provided in eight-to-ten 2-day sessions. For most families with young chil-



**Under IDEA, families are equal partners with professionals in determining the services and supports that are needed to address the developmental needs of their children.**

dren still enrolled in EI, this may be too large a time commitment, so other states modify training for parents of young children. New York also funds an Early Intervention Partners program. This program solicits applications from families from two regions of the state each year. Fifty parent applicants are chosen to attend a series of three 2-day sessions to learn more about the implementation of the state's Early Intervention Program. The review process of the applicants is important to highlight, as it is done with very intentional outcomes. Identifying leadership qualities, as opposed to only accepting well-written applications, is a key factor that ensures a diverse group of families are selected. These include a strong commitment and willingness to work on behalf of young children and their families, the ability to communicate their thoughts and ideas, their willingness and ability to collaborate effectively with professional partners and other family members, goals and a vision for the EI system of services, and supports at the local, state, and/or national levels.

In addition to adapting training to parents of young children and ensuring diverse representation among participants, the Early Intervention Partners training staff is also committed to a holistic "philosophy of support." Identifying family support needs begins by asking all families if they need additional support to attend the trainings. When families indicate they need support they begin a nonjudgmental discussion with staff to determine specific supports including special dietary or religious customs, translation assistance, or financial support for child care or transportation. By asking all families

if they have any support needs, families can have their needs met and the training reaches a wider audience of families. Once Early Intervention Partners graduates return to their local community, some join their county's EI coordinating council; others apply to join the state ICC.

Other states have contracts with programs to provide leadership training and support to the parents on the state ICC. States may contract with their Parent Training and Information Centers or Parent-to-Parent organizations to provide training, mentoring, and leadership support. This support assists families in establishing linkages directly with statewide organizations that serve families with children of all ages and all disabilities. The goals of leadership training generally are to assist families to gain the knowledge necessary to understand the history of the disability movement, to learn effective communication skills necessary to share their story (or the stories of others) for maximal impact, to gain a better understanding of best practices in services delivery, and to understand current policy issues facing the EI system in order to support collaboration with professionals in the development of effective policies at all levels of government.

Many states have expanded on the practice of merely providing families a seat on the ICC. Some states have hired experienced parents to provide parent support. In Massachusetts, the Part C Lead Agency went so far as to hire a parent as their Director of Family Initiatives program which oversees two parent-led and parent run projects. These projects work with families within the

EI system to encourage them to be involved above and beyond their EI services and support them along their journey. These programs serve as the Central Directory for EI as the first point of contact for families and are the parent-to-parent program for the state as well. A number of states employ professional parents in a number of different roles with the goal of ensuring meaningful parent involvement in their EI program. These family leaders may orient new parent members of the ICC to the council, showing them how to find the current state laws and regulations or sharing the ICC's past history. They also may facilitate regular conference calls for the ICC parents, creating an opportunity for parents to ask questions or test out positions prior to the ICC meeting. These conversations can assist parent representatives to think about the implications of policies for all families and to go beyond their own experiences. For example, policies are experienced differently by families who are enrolling their biological children in EI than they are by families enrolling foster children and have still different implications for families who are hoping to reunite with children in foster care. Parent representatives in their ICC role represent each of these families and raise their concerns.

Another strategy is the establishment of Family Leadership subcommittees on the state ICC. Many state councils have family leadership or family support subcommittees. These subcommittees serve as a way to enhance council parents' opportunities to communicate amongst themselves and with other council members, develop their ideas and agenda, and bring them to the awareness of the council as a whole. A strategy some of these committees use is to meet prior to their ICC meeting, so that parent representatives can complete their agenda and are then available to serve on the other subcommittees of their council, thus ensuring the parent perspective is represented in those venues as well. These committees can also develop tools to assist families and professionals in the field, providing tools such as checklists for the transition process or handbooks outlining the procedural safeguards available to families. They may hold forums to hear from families about their experiences with EI or to review draft documents. These meetings can provide valuable opportunities to discuss issues that are specific to families and can often include families who are not officially appointed to the ICC, but who can share their experiences and help to shape policy nonetheless.

Although many parents are professionals, many more are volunteers. At the policy level, travel and other expenses have increased exponentially. Many states have used creative

ways to support families to attend ICC meetings and relevant conferences, for example providing mileage reimbursement, child care, and stipends for missed employment time.

## Parents at National Conferences

**S**INCE THE INCEPTION of EI, family leaders have taken advantage of state and national gatherings to further their skills. Because each state varies in its policies and practices regarding the delivery of Part C services, attendance at national conferences offers parent leaders the opportunity to enhance their skills by becoming familiar with the variations in EI practice across the country. Attending state and national conferences also ensures that family leaders can connect with one another and learn the most up-to-date research, practices, and policies. States with parents as professional staff often travel with families to national conferences, mentoring them during, for example, their first national conference experiences, when they might be uncertain as what to expect. Mentoring can also assist families to understand the context of what is possible within their own state's system. Because Part C of IDEA allows states to determine which state agency will act as Lead Agency, and because each state determines its own definition of eligibility for its system, it can be very helpful for parents new to the ICC to have an experienced parent leader to explain why what may be working for one state may have to be reworked to "take it home" as a proposed policy change. In addition, professional staff often have immediate access to support funding. For many parents out-of-pocket costs and/or delays in reimbursement can prohibit their participation. Families who may not have credit cards or may not have enough discretionary cash are challenged to meet expenses and may be embarrassed to mention these concerns; professional parent staff can assist in navigating this issue, thus allowing emerging family leaders from diverse backgrounds to participate with dignity.

Many states have historically depended on federal sources of funds to support family leaders to attend state and national conferences. In the early years of EI, the U.S. Department of Education Office of Special Education Programs provided funds to the National Early Childhood Technical Assistance System to ensure that each state sent at least two parent leaders to their national early childhood conference. Most recently, Office of Special Education Programs has placed the expectation on states to use their own discretionary funds to support the travel of Part C staff and parent leaders to national conferences. The National Early Childhood Technical Assistance System (now a Technical Assistance Center) provides

a limited number of conference registration fee waivers (this does not cover any pre- or post-conference events) and one night's stay at the hotel for the 3-day conference at no charge. Families who do not receive support from their Part C program often apply to their state or local Developmental Disabilities Planning Council for grant assistance to cover the travel costs, food, and other night's lodgings. Despite these specific resources, support to families to attend national conferences has decreased over the course of years, and fewer states are supporting this practice.

## A National Organization for Part C Parents

**T**HE EARLY INTERVENTION Family Alliance (EIFA) was created by a group of parents who served as members or as chairs of state ICCs or who worked as staff supporting family leadership activities. At a national early childhood conference in 2004, a group of parents sat down to discuss what many saw as a growing absence of the family voice in the development of EI policies both within their states and in particular at the national level. In the past, it was the role of the FICC to represent the family perspective at the federal level, and FICC parents produced a number of products and other supports (e.g., family participation benchmarks) to ensure this took place. Once the FICC was eliminated by changes to the IDEA in 2004, this representation was no longer occurring.

These concerned parents also identified an emerging divide between families who were volunteering their time to support Part C EI and those who were in a professional role. (This division involved both family representatives and professional parents on their state ICCs as well as other roles.) The group had many discussions and in 2007 created a not-for-profit organization, the EIFA, made up equally of parents who volunteered on behalf of Part C in their state and parents in paid professional positions (such as parents who are also EI therapists, service coordinators, educators, etc.).

The EIFA is financed by organizational, professional, and family memberships, as well as by funding from the Beach Center and the IDEA Infant Toddler Coordinators Association. There are currently members from 25 states. EIFA has developed policy briefs critiquing proposed IDEA legislation and regulations from the family viewpoint, identified promising policies to support family leadership activities, and produced white papers including *Setting the Stage for Meaningful Family Involvement* (EIFA, 2007b). EIFA also developed the *A Conference at a Glance* (2007a) tool to assist families when they are planning to attend a statewide or national conference.



Photo: ©iStockphoto.com/Tomasz Markowski

**As families learn about their rights, they can be better advocates for their own child and family.**

This support document covers everything from questions to consider prior to the attending an event, to ways to prepare for the event, and suggestions to bring back to the state ICC upon returning home.

More recently, EIFA informs its membership of emerging issues at the national level through conference calls and email correspondence. Through collaboration with the IDEA Infant Toddler Coordinators Association, the EIFA provides regular Washington Updates to its membership. This enables the membership to understand what is happening in Washington, DC,

## Learn More

### EARLY INTERVENTION FAMILY ALLIANCE

[www.eifamilyalliance.org](http://www.eifamilyalliance.org)

The Early Intervention Family Alliance is a national group of family leaders dedicated to improving outcomes for infants and toddlers with disabilities and their families. The EIFA works to ensure meaningful family involvement in the development of Part C policies and their implementation at community, state, and federal levels.

### TA ALLIANCE FOR PARENT CENTERS

[www.taalliance.org/ptidirectory/index.asp](http://www.taalliance.org/ptidirectory/index.asp)

Funded through the U.S. Department of Education under the Individuals With Disabilities Education Act (IDEA) to provide information and training to parents of children with disabilities. Every state has at least one Parent Center, and those with large populations may have more.

and how changes to laws, regulations, and funding mechanisms will have an impact on EI. EIFA members provided comments for the U.S. Department of Education “listening tours” in 2010 and are considering comments to be made when the IDEA reauthorization takes place. In a specific state-level example, in Massachusetts family advocates generated 90% of the comments submitted in public hearings about changes in financing for EI services. As in other areas of disability policy, parents and family members have consistently taken the lead in advocating for improvements and best practices in disability services and supports, and this remains the case in EI at all levels.

## Conclusion

**R**EPRESENTING THE PARENT perspective in the continuing operation of EI services requires diligence on the part of family leadership and vigilance to ensure ongoing and meaningful engagement of families in all levels of policy and advocacy. Because EI serves only the youngest children and families are only involved in the system for their child’s first 3 years, there is ongoing turnover of families.

Growing the parent network is critical to making sure that every family, professional, and state system receives information about emerging issues that affect the EI system within the state and on the national level. Supporting emerging parent leaders and helping them to be strong systems advocates must be continued. New advocacy is needed to respond to the changing face of EI and family support services as a whole. There is considerable literature historically about the role of parents and family members in early childhood development, but there remains a relative dearth of current research on the role of families in early education particularly in regards to the family perspective in policy and legislative functions. Given the recent emphases emerging in the field on child and family outcomes, this area of investigation would be of particular importance regarding the efficacy of current and proposed practices around family

involvement. This is an example of a philosophy that is generally accepted as best practice within the field, but lacks up-to-date data in support of the belief that family involvement at all levels of EI policy and practice leads to better systemic outcomes.

Many families stand ready to step up in support of the services their family and other families benefitted from. Numerous known and certainly some yet unknown challenges await the field in regard to the provision of high-quality EI services to all children in order they be best prepared for their entry into the education system and beyond. All programs serving families of infants and toddlers should adhere to the *Principles of Family Involvement* (Smith & Hansen, 1998) to strengthen the family perspective in program design, implementation, and accountability. Meaningfully engaging families in federal and state policy development, providing parents with knowledge and advocacy skills, and gathering evidence to support the efficacy of parent-professional partnerships would ready the field to successfully meet these challenges. ❖

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**MARK A. SMITH, MS**, is the parent of a son who graduated from EI services. He is currently employed as the individual and family program coordinator at the Munroe-Meyer Institute for Genetics and Rehabilitation at the University of Nebraska Medical Center. Among his duties there is serving as a technical advisor to the Nebraska EI program, the Early Development Network. He formerly served as the vice-chair of the Nebraska Interagency Coordinating Council and as committee chairperson for the Family Empowerment subcommittee of the Federal Interagency Coordinating Council, and is a founding member of the Early Intervention Family Alliance (EIFA).

**DARLA GUNDLER** is the parent of a daughter who received EI services. She currently serves as the director of the Early Intervention Parent Leadership Project and as technical advisor to the state Interagency Coordinating Council for the Massachusetts Department of Public Health. In her roles, she works to inform families about

the variety of opportunities to actively participate within the EI system: at the local program, within their geographic region, and at the statewide level. The Project produces a newsletter, “The Parent Perspective,” five times a year which is distributed to more than 5,000 families within Massachusetts. She previously served as a parent representative for Massachusetts Interagency Coordinating Council and is a founding member of the EIFA.

**MAUREEN CASEY, MA**, is the parent of 12-year-old graduate of EI services. She currently works designing and delivering online training and content on the EI program in New York State to families across the state. She is working at the Just Kids Foundation as a curriculum designer developing an online curriculum and learning community for families enrolled in the New York State Early Intervention Program. She also worked in other projects around parent and professional training on leadership, natural environments, functional outcomes, and family support in EI. She served as vice-chair of the New York State Early Intervention Interagency Coordinating Council and as the New York State Family Voices Coordinator. She currently serves as the chairperson of the Arizona State Interagency Coordinating Council and as co-coordinator of the Arizona Chapter of Family Voices, and is also a founding member of the EIFA.

**TALINA JONES** is the parent of a 6-year-old boy with Down syndrome who has graduated from EI services. She is currently a trainer on the Early Intervention Partners Training Project, sponsored by the New York State Department of Health. This leadership project assists families enrolled in the EI to develop their advocacy skills on behalf of their child and the EI system and to understand the historical underpinnings of the disability movement and the critical role of parents. She is currently vice chair of the New York State Early Intervention Coordinating Council, a member of the Reimbursement Advisory Panel and the Group Developmental Workgroup for the EICC. Talina is a board member of New York State Parent to Parent and a member of the Board of Directors of the Jowonio School in Syracuse, NY. She is also a board member of the EIFA.

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# Changing What You Know and Do

## *The Parent–Child Psychotherapy Program*

BETTY ANN KAPLAN

JAMES VENZA

*Reginald S. Lourie Center for Infants and Young Children  
Rockville, Maryland*

If you're happy and you know it, clap your hands (clap, clap). If you're happy and you know it, clap your hands (clap, clap). If you're happy and you know it, then your face will surely show it, if you're happy and you know it, clap your hands! (clap, clap)

*Carmen's round young face beamed and her eyes shone brightly. She clapped her hands and smiled with delight. She was happy, and her body knew it! How old she was in that moment was unclear. This 22-year-old woman, a Latina immigrant from El Salvador and mother of two was herself, momentarily, a young child. Her face mirrored the expression on the face of her little boy, 3-year-old Matteo who, safely seated in the lap of the therapist across the welcome circle, gazed at her with a parallel delight.*

*Matteo had been removed from his mother's care 1 year earlier because of medical neglect. Diagnosed in infancy with failure to thrive, he was dangerously malnourished. Carmen and her family had been under the anxious scrutiny of doctors and nurses, social workers, developmental specialists, and the court. In an effort to keep Matteo adequately nourished and cared for by his mother and developmentally on course, a team of in-home therapists worked with Carmen and Matteo. He was intubated and received food through a feeding tube, the mechanics of which Carmen could not or would not master. She was unable to feed Matteo. She responded to her feelings of helplessness and shame by withdrawing from her son and angrily rejecting the help that was offered to her. Matteo did not thrive and she felt herself to be a failure. The moments that Matteo and Carmen shared in those days were anything but happy . . . and she knew it.*

### The Parent–Child Psychotherapy Program

THE PARENT–CHILD PSYCHOTHERAPY Program (PPP) is a multifamily group intervention model designed to serve disadvantaged families with multiple and complex risk factors for intergenerational patterns of abuse, neglect, and attachment disorganization. The risk factors these parents face include: environmental and psychosocial stressors of poverty, employment pressure, acculturation stress, and unsafe neighborhoods. Internal risk factors also present real challenges to parents—specifically, the lasting effects of negative early childhood experiences and trauma. Cumulative and negative early childhood experiences develop into internal work-

ing models of attachment relationships that are insecure or, with trauma present, often disorganized. These internal risk factors powerfully predict the quality of parent–child relationships and negative long-term developmental outcomes for children (Solomon & George, 1999).

When a child comes into the world with medical or constitutional difficulties, such as prematurity; regulatory problems related to sensory processing; and concomitant challenges with sleep, feeding, or self-soothing, a parent with limited external or internal resources is severely challenged. Under consistently overwhelming stress, parents go to what they know. They often show in their behaviors what they themselves experienced as children at the hands of their own parents.

This continuity of parenting has clear support in the research (Sroufe, Egeland, Carlson, & Collins, 2005). With alarming predictability, parents enact patterns of abuse and neglect in their own families and need the protection of Child Welfare Services. This troubled road led Carmen and her children, and other families like hers, to the PPP at the Reginald S. Lourie

### Abstract

The Parent–Child Psychotherapy Program (PPP) is a multifamily group therapy intervention for parents and young children at high risk for intergenerational patterns of neglect, abuse, and disorganized attachment. A “developmental and experiential model” that incorporates principles of attachment theory, the PPP addresses parent and child needs simultaneously in the context of structured activities, free play, and separate parent- and child-only groups. Therapeutic objectives aim to shift parents' internal working models of relationship toward increasing attachment security, to change parent–child behaviors to promote safety and exploration, to build a foundation for parent–therapist collaboration, and to propel children's healthy development in a safe, predictable, and emotionally attuned environment. The authors present the history of the PPP, its underlying assumptions, and specific interventions with a family.



**Parents must be understood and nurtured before they can understand and nurture their children.**

Center for Infants and Young Children by way of Child Welfare Services, Montgomery County Infants and Toddlers Program, and other community referral sources.

The Lourie Center has long been a leader in early intervention programs supporting infants, young children, and families, especially those at high risk for abuse and neglect. The Center originated in the 1980s as a result of a National Institutes of Health grant-supported collaboration among a stellar multidisciplinary group of research-minded clinicians including Reginald Lourie, Stanley Greenspan, Serena Weider, T. Berry Brazelton, Bob and Amy Nover, Alicia Lieberman, and Mary Robinson (Greenspan et al., 1987). The PPP grew out of this collaboration and shared many assumptions and methods with infant-parent psychotherapy programs developing throughout the country (Nathanson, Craft, Williams, Castellan, & West, 1991). With strong ties to psychoanalytic object relations theory (Fraiberg, Adelson, & Shapiro, 1975; Lieberman, Padron, Van Horn, & Harris, 2005) and influenced by research in developmental psychology—notably, infant development (Brazelton, Koslowski, & Main, 1974)—this team pioneered efforts in early intervention and became a model for the mental health community (DeGangi & Poisson, 1991; Greenspan, DeGangi, & Wieder, 2001). At the time that John Bowlby's paradigm-changing theory of attachment (Ainsworth, Blehar, Waters, & Wall, 1978; Bowlby, 1969/1982) was debated in the institutes and universities in the United States and abroad, clinicians in the field of

infant mental health recognized the critical importance of the mother-infant relationship and its potential for supporting robust, healthy child development (Hesse & Main, 2000; Main, Kaplan, & Cassidy, 1985; Zeanah & Boris, 2000). Currently, the proliferation of early intervention programs and models of attachment-focused psychotherapy (Berlin, Zeanah, & Lieberman, 2008; Steele, Murphy, & Steele, 2010) attests to the assumption that a strong and secure parent-child relationship is the best predictor of a child's developmental success.

The PPP model is based on the philosophy that for adults to be able to parent in caring and nurturing ways they need to have actually experienced a caring and nurturing relationship at some point in their development. Parents must be understood and nurtured before they can understand and nurture their children.

The PPP is designed to shift parent and child behavior in the direction of increasing attachment security and emotional attunement. Ultimately, both parents and children develop internal working models of relationship characterized by safety, responsiveness, mutuality, and mastery. The PPP addresses change along three basic therapeutic dimensions: parents' internal working models, parenting behaviors, and the parents' relationship with therapists (Berlin et al., 2008). In addition, the PPP views the child as an active contributor to change and supports the child's response to a parent that is appropriate to the child's stage of development. The overarching goal of the PPP is to provide both the "safe haven" and the "secure

base" (Marvin, Cooper, Hoffman, & Powell, 2002) from which both parents and children can grow. To advance this goal, the PPP uses an experiential and developmental model of intervention. Parents and children are simultaneously supported at their respective social and emotional levels within the context of the parent-child relationship. In a group context, parents and children with similar needs observe, interact with, and support each other. The group experience places parents' challenges within an increasingly normative context where progress and gains are celebrated.

### ***Assumptions and Rationale of the PPP Model***

**Assumption 1:** Early intervention that simultaneously works with the parent and child is crucial in preventing patterns of abuse, neglect, and attachment disorganization.

**Rationale:** Families coping with intergenerational neglect and abuse require intensive, comprehensive intervention to transform cycles of loss and violence. Parents who struggle with abuse or neglect neither recognize nor respond to their child's emotional needs in the moment, especially under stress when their own attachment pattern is activated. The PPP model simultaneously works to support the development of parents and children individually and within parent-child interactions. Increased parental emotional availability and attunement to their children and their children's positive responses lead to greater security of attachment. The parent and child's sharing of playful experiences during free play, structured play, and mealtime provides fertile ground for changing negative patterns of parent-child relating. As a parent becomes more responsive and in tune with a child, he becomes better able to take pleasure in the child's development, to understand and eventually to reflect on the meaning of a child's behavior in the context of development, and to enjoy his child. The PPP provides opportunities for parents to pause, look, listen, and think about their child's experience before responding.

**Assumption 2:** Parental self-esteem increases as parents experience safe and reciprocal interactions with their children.

**Rationale:** A parent's self-esteem is, in part, a reflection of her representation of herself within past intimate relationships. Parents who have experienced emotional pain and loss, or trauma in a primary relationship with their own parent, translate their assumptions of rejection, abandonment, or hurt to their current relationships with their own children. On the basis of past history, parents may distance themselves, distort and confuse their child's communications, or even make preemptive attacks to avoid the

anticipated pain of intimate relationships. Experiencing success in her relationship with her child, a parent can repair her own emotional pain and construct an alternate, positive representation of herself as a parent. As a parent recognizes her own contributions to the child's behavior, she can take pride in promoting the child's development. Successful parenting then enhances and perpetuates parental self-esteem.

**Assumption 3:** Parents must experience the pleasure of small successes on a concrete level before being able to shift to a more abstract level of pride and pleasure in their child.

**Rationale:** In this experiential model, parents are encouraged to practice new behaviors. Parents learn how to read their child's cues and praise their "good" behavior as well as how to set firm and effective limits. Parents experience the success of organizing their child's behavior through consistent, predictable family routines. Parents feel more regulated, effective, pleased with competency, and they become increasingly able to think about their child and take satisfaction in their child's accomplishments. Over time, parents appreciate that their children's intentions, feelings, and behaviors are different from their own.

**Assumption 4:** Providing early intervention to children in high-risk families helps to buffer them from the ongoing family disorganization and environmental challenges that they face.

**Rationale:** Parents may have deeply entrenched psychosocial difficulties that require long-term treatment. Early intervention is key to support children's social-emotional development and reduce the probability of poor developmental outcomes. Within the group format, children have the opportunity to form more secure relationships with staff and parents. The group process provides a safe, predictable environment in which a child can learn more cooperative and collaborative behaviors. Competent social interaction with peers and adults is modeled. New relationship experiences based on safety and support help alter a child's expectations and behavior and shift his developmental trajectory in a more positive direction.

**Assumption 5:** A group experiential model is more effective than individual psychotherapy for most parents with disorganized attachments and histories of abuse and neglect.

**Rationale:** A safe, well-regulated group format with multiple staff for parents and children represents a goodness-of-fit experience for individuals with attachment disorganization. The model creates a less threatening or intimate interpersonal atmosphere designed not to activate attachment



PHOTO: ©ISTOCKPHOTO.COM/KIM GUNDEL

**Early intervention is key to supporting children's social-emotional development and reducing the probability of poor developmental outcomes.**

needs that may lead to disorganization in traumatized parents and children. The pressure for individual members to interact is greatly reduced in a group of six or more adults, compared with individual psychotherapy. With multiple staff members, parents can reveal differing parts of their emotional experience to different staff, thereby protecting the fragile sense of self that many parents struggle with. Over time, parents come to trust the group process as well as to develop specific relationships with individual staff. With the consistency and predictability of these interactions, parents become more ready for individual or dyadic therapy.

**Assumption 6:** In high-risk families, parents need to be positively nurtured and supported.

**Rationale:** Parents with traumatic and disorganized attachment histories view the role of parent negatively. They frequently experience their child's behaviors as rejecting, abandoning, or attacking, on the basis of their own internal working models of relationship. The group model effectively counters this ambivalence by identifying and reinforcing the critical role of each parent and the specialness of each parent-child dyad.

**Assumption 7:** Parents need to experience and practice verbal means to express themselves.

**Rationale:** Many parents who participate in the PPP lack the experience of putting thoughts and feelings into a verbal mode. Instead, feelings and thoughts are communicated through action alone. As children, thoughts and feelings were typically met

with dismissal, rejection, or abuse. The group demonstrates an attitude of curiosity and a genuine interest in hearing what a parent needs, wants, thinks, or feels. Staff members accomplish this task by incorporating parents' feelings and ideas into the group, whether by adding a new song, a new dance, or a new activity.

**Assumption 8:** High-risk parents benefit from learning how to play with their children.

**Rationale:** Many parents lack the experience of playing in a safe context. Early experiences of abuse and neglect leave parents tense, startle-prone, and wary. Ambiguity is met with suspicion and negative interpretation. Parents cannot be expected to understand or take pleasure in their child's play when they have not had a parallel experience. In the PPP, parents are encouraged and admired as they play with their children. At times, parents suspend their role as parent and get lost in the play and get immersed in spontaneous joy and delight. With repeated experiences, parents assume the parent role and now enter their child's play in a nondirective manner and experience the gratification of competently supporting their child's play in a safe environment, both physically and emotionally.

## Inside the PPP

**A** TYPICAL PPP GROUP ranges in size from four to six families with 5–8 children. The staff-client ratio is low so that safety is ensured and children and adults can experience individualized attention along with group activities. Parents are encouraged to bring children 4 years old or



**As a parent becomes more responsive and in tune with a child, he becomes better able to take pleasure in the child's development.**

younger who are not enrolled in preschool programs. Staff consists of mental health professionals including psychologists, social workers, and graduate trainees. The groups are either English- or Spanish-speaking, and at least two bilingual therapists participate in groups that include families in which English is a second language. Groups generally last 90 minutes and are divided into two segments. The first segment includes joint parent-child activities, and the second part consists of "parent-only" and "child-only" groups. The group is organized in the following manner.

**Welcome circle:** Children and parents sing songs together and take turns learning new ways to recognize and value each other. Children and parents are individually recognized, and cultural differences are expressed and celebrated.

**Arts and crafts projects:** These projects are specially designed as developmental opportunities to support parent-child interactions around exploration and self-expression. In the initial stage of a group, parents often focus on completing their own projects and are encouraged and supported by staff. Over time, parents shift their focus to support their children's exploration and mastery. Parents are consistently oriented toward reading and responding to their child's cues, whether for help or for praise. The focus of this phase is the process and quality of working together.

**Parent-child free play:** This phase serves to help parents practice their looking, listening, and reflecting skills alongside a therapist. Parents also experience what it is like to follow the child's lead, elaborate the child's play through positive structuring, more accurately

read changes in their child, and register how the child's behavior affects their own thinking and feeling. Staff members model these skills during direct or indirect support of the child.

**Mealtime:** A healthy snack is prepared by the staff to concretely nurture parents and children. Positive family routines are developed with the idea that mealtimes can be an enjoyable social event.

**Separation:** The parent group and the child group meet in different rooms. Parents have the opportunity to share observations and concerns that affect their ability to care for their child in a supportive context with other parents facilitated by staff. They also explore how their own childhood and parents affect their ways of thinking, feeling, and behaving today. The children's group takes place in the familiar room. They have a safe, emotionally responsive context to practice new skills, develop peer relationships, and practice with staff safe separations and reunions with their parents.

**Reunification:** Positive reunification between parents and children is supported. In the closing good-bye circle, each parent and child is again recognized and valued. The next meeting is anticipated and discussed. This routine provides for emotional regulation of both parents and children as they transition out of the group to meet the day.

### **Specific Interventions: One Family's Participation**

The PPP implements carefully designed interventions that address the unique needs of each family in the group. Below we illustrate the use of these interventions with a very special mother and her children.

1. The intake process is abbreviated to provide an immediate and positive experience of the group process. After an initial meeting with a parent, a "mini-PPP" session is held to introduce the parent and child to the group routine and alleviate anxiety about therapy services. Because many families are referred from Child Protective Services, a deliberate uncoupling of the courts and social service agencies from the PPP is made to emphasize confidentiality and promote trust. The tone is positive, nonintrusive, and reinforcing. The family is invited back to meet with other parents the following week or as soon as possible.

*Carmen was deeply suspicious of the group program. PPP was court ordered, and her initial perception of participation was, "OK, one more thing to get my kid back home." In other words, there was nothing in it for her. The mini-PPP surprised her. Two clinicians, one fully bilingual, welcomed her and her two children with understanding and appreciation. She was invited to share a song in her own language that the clinicians learned.*

2. The program provides a safe, predictable environment for children and their parents. Staff is trained from an attachment perspective to be sensitive and responsive and to provide structure, routines, and positive limit setting. They provide the external structure that parents may need when their internal controls are threatened by heightened emotional states. These measures give families a sense of safety; parents know that staff will not let them lose control and act out scary or angry feelings by hurting themselves or others. The routines of the group are predictable.

*Week after week, Carmen and her children could expect that their needs for safety and security would be met. Whereas Matteo was preoccupied with his mother's states of mind, his little brother Jose, 18 months-old, was disorganized and oppositional. He had little experience with nonpunitive limit setting or a sensitive response to his behavior. Initially, Jose refused to join the group; he ran away and crawled under the table, his eyes wide and his thumb firmly inserted in his mouth. Carmen was embarrassed and angry. She raised her voice and physically threatened him if he didn't behave. While one clinician sat quietly near Jose, another labeled Jose's behavior as timid and frightened, stating calmly, "new people and places can be scary." Staff encouraged Carmen to let him settle down and allow him to decide when he felt it was safe to join the group. Although she too was uncertain of whom she could trust, the familiar routine and reassuring response of the clinicians allowed her to participate and let the group activity help regulate her own anxiety.*



3. The staff provides nurturing to parents on both a concrete and a verbal level. Concrete nurturing means providing support at an observable or physical level, such as greeting with a smile, offering an affectionate pat, or sharing food. Verbal and gestural communications are made through clear facial expressions or intonations that convey appreciation, understanding, and care.

*Because feeding had been such a difficult problem between Carmen and Matteo, the staff was especially sensitive around taking over Carmen's role during snack times. The mothers in the group spontaneously decided to bring their own contributions on occasion. When Carmen showed up with a flan one morning, she was admired and appreciated for the delicious treat. Matteo and Jose shared their mother's pride and showed it by cleaning their bowls!*

4. The staff protects the parent or child when he is in pain or danger. For a parent, this may mean individualized attention to allow a parent to express distress over a negative interaction with his child. For the child, this may mean staffers substitute for a parent who is nonreactive to a child's needs or puts limits on an overly reactive parent behavior. The staff may need to comfort a child who is in significant distress, even if the parent objects and is overwhelmed by his own internal distress. A staff member verbally acknowledges a parent's wish and states clearly that the child's emotional needs are critical in the moment. Another staff member closes the circle with the parent to be sure that he feels heard and validated.

*Matteo often expressed his anxiety when Carmen would ready herself to leave for the parents' portion of the group. Standing rigidly with a "hangdog" expression, Carmen would push Matteo away and admonish him to act like a "big boy." Staff would speak to Carmen's belief that self-sufficiency was necessary for survival while labeling Matteo's need in that moment for the reassurance that she would return.*

5. The staff provides parallel treatment to support the child and the parent's emotional development. Most parents who participate in the PPP are struggling with emotional issues similar to those of their child, such as feeling protected and safe and asserting one's own autonomy. Staff encourages both children and parents to assert their needs verbally and gesturally. Staff creates a safe environment for thoughts, feelings, and behaviors.

*Carmen struggled in the parent group with her own ambivalence with dependence.*



PHOTO: THE LOURIE CENTER

**During the Parent Child Psychotherapy Program at the Lourie Center, the parent and child's sharing of playful experiences provides fertile ground for changing negative patterns of parent-child relating.**

*Having traumatically lost her mother as a young child and having been raised in an exploitative and abusive adult environment, Carmen learned early that her survival depended on her ability to take care of herself. The idea of depending on other people was risky at best and, more often, resonated with her own experiences of danger and helplessness. In the parent group, Carmen began to test out her thoughts and feelings. After she was reunified with her child and her participation in the PPP was no longer "required," she allowed the staff and other mothers to listen to her uncertainty and to support her desire to continue in the group. She was beginning to develop a belief that perhaps she and her children could have needs that could be met in reliable ways.*

6. The staff makes direct verbal connections between the child's feeling states and those of the parent. At times, a child may give voice to a parent's unexpressed feelings through action. At other times, the parent may interpret a child's behavior as though it were a projection of what she was thinking or feeling. Staff will draw the boundary and put words to what each member of the dyad may be experiencing.

*Carmen had difficulty expressing her anger and frustration with the staff directly. Sometimes she would be a "no-show" at the group. At other times, she would say things like, "Matteo is mad at you today," or "Matteo was so mad at Ms. S. (caseworker) who made him late today." Staff might say something like, "I know it's hard for you,*

*Carmen, to feel angry and to tell us about it. I think you are actually angry because we missed group last week or at having to wait today for the cab, and not Matteo. It's okay to feel angry and to tell us in words." As time went on, staff could identify sad feelings in Matteo and wonder whether maybe Carmen might be feeling sad about something, too.*

7. Staff supports both the parent and the child when the child protests with anger or sadness. Many parents have difficulty allowing a child to feel or express strong emotions. When this occurs, one staff member is responsive and supportive of the child while another helps the parent to tolerate a display of an emotional need (within safe limits) and to wonder about its meaning. Parents who have not had responsive and containing emotional experiences as children are supported and praised for accomplishing the difficult task of differentiating their own experience from that of their child.

*Over time, both Matteo and Jose had trouble leaving the group. Matteo would rock in his chair with a stubborn grimace, and little Jose would race around the room, evading attempts to physically contain him. Progress was clear when Carmen would shake her head sadly and state, "They're mad, they just don't want to leave." Staff now reinforced her ability to think about their feelings and behavior and say to her, "It's so good that you can understand how they are feeling, because you know how hard it is to leave."*

8. The staff helps parents to read their children's cues. Talking through the child is a technique used to highlight the meaning of a child's behavior and put it into a developmental context. Talking through the child focuses on the child's experience rather than on what is right or wrong.

Staff speaking for Matteo would say to Carmen, "I feel sure you will come back soon. I can wave and say good-bye and play with my friends. See you later, Mom!"

9. Staff label the child's and the parent's feelings.

To Jose, who frequently acted on his anger, staff might say, "You are telling me you are mad when you kick walls and slam doors," or to Carmen, "By your silence today, you are telling us how angry you are for having to wait so long to be called back on the telephone."

10. Staff helps parents separate their needs from their child's and identify the meaning of their own behavior.

In the presence of Carmen's withdrawal, a staff member said to Jose, "Your mom isn't coming over to you because she has some grown-up worries and not because you did something wrong."

11. Staff members reframe disparaging parental comments about their child's personality or needs. When a parent labels his child as "stubborn," staff may tell the parent "your child is very determined and doesn't give up easily."

Because of developmental delays, Jose had difficulty expressing himself verbally. He avoided eye contact, stammered, or even struck out in frustration when the words did not come. At times, Carmen expressed her frustration by labeling him a "bebe" (baby) or even a "bobo" (silly boy). Staff countered with, "Carmen, Jose has so

much he wants to say, he can't say things fast enough," or "He's learning not one, but two languages. What a smart boy he is!"

## Conclusion

"IF YOU'RE SAD and you know it, cry boo hoo. If you're sad and you know it, cry boo hoo. If you're sad and you know it, then your face will surely show it, if you're sad and you know it, cry boo hoo. Boo hoo!"

Carmen, Matteo, and Jose stayed with the PPP group for 8 months, including 2 months of voluntary participation. Matteo returned to live at home with his family. The children were headed to preschool, with Matteo entering the specialized Preschool Education Program in the coming months. There was hope that Carmen would return to the Center in the fall. Perhaps she and her children could benefit from a more intensive therapeutic intervention, but Carmen was determined to be "independent," and she still had deep ambivalence around relationships. The experience that she and the children had during their time in the group had been predictable, safe, and nurturing. It was not dangerous to express feelings and thoughts. On the contrary, Carmen experienced being a parent who could take pleasure in herself and her children and discovered new ways of understanding and responding to their behavior. The groundwork was laid for more secure parent-child relationships and the hope for better outcomes for both mother and children. All attachments by definition are reciprocal, and the staff certainly cared and would miss this family. They were sad to say good-bye, but they were also secure in the knowledge that Carmen would hold the Lourie Center in her mind, and if she or the children needed to, they would return. §

BETTY ANN KAPLAN, PhD, is a licensed psychologist and director of Parent-Child Clinical Services

and Child Placement Consultation Team at the Reginald S. Lourie Center for Infants and Young Children and is in private practice offering adult, child, couple, and infant-parent psychotherapy. She has worked in the field of infant mental health and early intervention for more than 20 years. She has taught, published, and presented the work of the Reginald S. Lourie Center on clinical applications of attachment theory and methodology and is interested in intergenerational transmission of trauma. She is the former co-chair of the Advanced Psychotherapy Training Program at the Washington School of Psychiatry in Washington, DC. She has a private practice in Rockville, MD.

JAMES VENZA, PhD, is a licensed psychologist and associate executive director of the Reginald S. Lourie Center for Infants and Young Children, Rockville, MD. He supports the Lourie Center's mission of improving the emotional health of children and families through early prevention, clinical intervention, education, research, and training. He directs the Center's Therapeutic Nursery Program, a specialized preschool program that integrates early childhood education and social-emotional development. He is also a member of the Center's Child Placement Consultation Team, which conducts forensic evaluations of parent-child relationships. As a faculty member of the Washington School of Psychiatry, he participates in the Infant and Young Child Mental Health Seminar. He has presented at local and national conferences on attachment theory, trauma, and social-emotional development. He is part of an ongoing, collaborative project in Port au Prince, Haiti, that supports the emotional health of children and adults coping with the traumatic effects of the January 12, 2010, earthquake.

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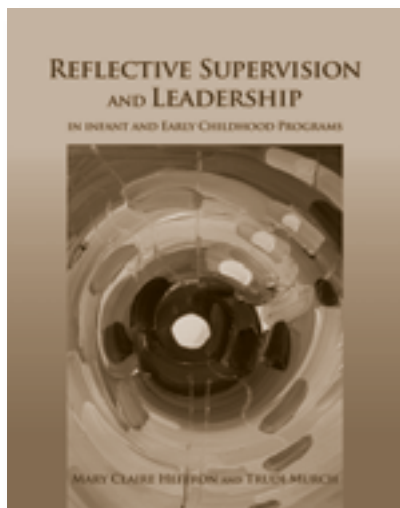
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National Center for Infants, Toddlers, and Families

# Building on the Foundations of Part C Legislation

## *Beginning the Conversation for Reauthorization*

PATRICIA COLE

CINDY OSER

*ZERO TO THREE, Washington, DC*

SHARON WALSH

*Division for Early Childhood, Missoula, Montana*

*IDEA Infant Toddler Coordinators Association, Indianapolis, Indiana*

In the field of early childhood, it is often said that early experience matters, meaning that along with biological and genetic influences, a baby's relationships, environment, and everyday interactions have a very significant influence on the architecture—the sturdy or fragile foundation—of the developing brain. In the years since the Part C Early Intervention Program of the federal Individuals With Disabilities Education Act (IDEA, 2004) was first enacted, science has significantly enhanced early childhood professionals' knowledge of child development and how they can best support the health, mental health, development, and learning of infants and toddlers. Although infants and toddlers grow and develop at different rates, most follow a predictable path and walk, talk, and learn in predictable ways. For others, development unfolds slowly, or in an atypical fashion, or sometimes does not progress beyond the first months and years. For these infants with a developmental delay or disability, intervening early can make all the difference in the world. Early intervention enhances the capacity of families to promote the best possible developmental outcomes in their children and reduces the need for more intensive and costly special education services later in life. Early intervention works. In fact, some young children who receive early intervention may not need any additional services after the first few years and others may need services of less intensity. The Part C Early Intervention Program is the major vehicle to make sure this happens.

The phrase early experience matters provides a useful way to think about the development of the Part C program. Just as the early years of a child's development create the architecture of brain connections, the early years following enactment of federal Part C legislation was foundational to the growth that must now occur. When enacted

in 1986, P.L. 99-457—the legislation that created the early intervention program now known as Part C—provided a structure for comprehensive statewide early intervention services (see box What Is Part C). However, as professionals plan for the next reauthorization of Part C they must now take advantage of policy opportunities to make renovations

and secure adequate and sustainable financing to ensure future success for all children with disabilities and their families.

In this article, we explore current issues that challenge Part C and outline some policy questions that can help begin conversations about what changes should be made to reinforce the foundations of Part C and assist

### **Abstract**

**Just as the early years of a child's development create the architecture for future brain growth, early implementation of federal Part C legislation laid the groundwork for a system of supports for families of infants and toddlers with disabilities. Some aspects of the current legislation provide a sturdy foundation for sound policies and effective practice. In other areas, the legislative foundation needs improvement. The 25th anniversary of Part C and the upcoming reauthorization of the program offer opportunities to consider changes to current federal legislation. This article explores issues challenging Part C implementation, and identifies policy areas that can be considered as reauthorization conversations begin.**

## WHAT IS PART C?

Part C authorizes and provides federal assistance for states to maintain and implement statewide systems of early intervention services for eligible children, from birth to 2 years old, and their families. Part C is a discretionary program, which means that states may choose to participate or not. If they do participate, they must fully implement the statutory requirements of the law.

All states and eligible jurisdictions are currently participating in the Part C program. Each state receives annual funding under this legislation on the basis of the number of children less than 3 years of age in its population. Under Part C, states and jurisdictions must provide early intervention services to any child (and the child's family) who is less than 3 and who is experiencing developmental delays or has a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay. In addition, states may also choose to provide services for infants and toddlers who are "at risk" for serious developmental problems, defined by circumstances (including biological or environmental conditions or both) that will seriously affect the child's development unless interventions are provided.

Under the current law, Congress must periodically review and reauthorize Parts C and D of IDEA (usually every 5 years) to ensure the continuation of their programs and services. Part B, the section of the legislation that authorizes special education and related services for children 3 through 21 years old, is authorized permanently.

in ensuring a stronger, more effective system of supports for families of infants and toddlers with disabilities. These policy questions could lead to renovations that would improve quality, strengthen systems, and create a qualified and sufficient workforce to provide services. We conclude with suggestions for what individuals can do to become more involved in improving federal, state, and local early intervention policy.

### Background

CONGRESS ESTABLISHED PART C (originally known as "Part H") of IDEA in 1986 under P.L. 99-457 to respond to "an urgent and substantial need" to:

- Enhance the development of infants and toddlers with disabilities;



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**A baby's relationships, environment, and everyday interactions have a significant influence on the architecture of the developing brain.**

- Reduce educational costs by minimizing the need for special education through early intervention;
- Minimize the likelihood of institutionalization, and maximize independent living; and
- Enhance the capacity of families to meet their child's needs (IDEA, 2004).

Prior to the passage of P.L. 99-457, there were no entitlements to services for infants and toddlers with disabilities. Part C's highest achievement in its 25 years of existence has been using a relatively small amount of federal funding to leverage a system for addressing the needs of infants and toddlers with disabilities and their families in every state and eligible jurisdiction. Over the past 10 years, as the national fiscal crisis grew, some states have considered not participating in the program. During the most recent economic downturn, it was reported that nine states discussed dropping out of the federal program. Although no states have actually dropped out since Part C was enacted, the number of states actively discussing this possibility is an indicator of state budget deficits, insufficient federal fiscal support, and a reaction to increasing federal requirements without adequate federal investments in this important program.

As this article went to press, all states and six additional eligible jurisdictions are participating in this voluntary program, agreeing to ensure that young children with disabilities and their families are provided with

early intervention services in accordance with an Individualized Family Service Plan (IFSP). As a result of Part C of IDEA, children whose developmental issues previously might have been overlooked or whose parents may have had nowhere to turn for help, have the right to be evaluated and to access services if eligible.

Part C intended each state to create its own statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers with disabilities and their families. Federal funds were to be used to help connect and coordinate all available federal, state, and local public and private sources of funding, and not necessarily to be a primary payor for early intervention services to children and families. Change and variation continue to characterize the state Part C programs. As the federal law allows, the 56 state systems are led by agencies of their own choosing; about half (24) are led by health agencies, while 14 are led by education agencies, and the remainder (18) by other agencies including social services, mental health, and disability agencies. Financing mechanisms, provider relationships, eligibility criteria, leadership, standards, and personnel qualifications also vary across participating states and jurisdictions (IDEA Infant Toddler Coordinators Association, 2010b).

Although much progress has been made in the 25 years since passage of P.L. 99-457 (see box Brief History of IDEA and Part C), some fundamental challenges remain: lack of federal funding, state budget deficits, changing policy priorities, shifts in service delivery focus,

## BRIEF HISTORY OF IDEA AND PART C

- 1975: Passage of Public Law 94-142, Education for All Handicapped Children Act, which mandated services for children and youth from 3-21 years old, consistent with state law.
- 1986: Education for the Handicapped Act amended by Public Law 99-457 to support states to serve children with disabilities beginning at birth, established Part H, Programs for Infants and Toddlers with Disabilities.
- 1990: Education for the Handicapped Act further amended by Public Law 101-476, and name changed to Individuals With Disabilities Education Act (IDEA).
- 1997: IDEA re-authorized and sections consolidated; Part H becomes Part C.
- 2004: Part C reauthorized

IDEA has four parts:

- Part A: General Provisions
- Part B: Assistance for Education of All Children With Disabilities
- Part C: Infants and Toddlers With Disabilities
- Part D: National Activities to Improve the Education of Children With Disabilities

The next reauthorization of IDEA is expected to be on the agenda for Congress after the reauthorization of the Elementary and Secondary Education Act, which is on the calendar for consideration in 2011.

Part C regulations were issued for public comment in 2007 but there has been no official release date for publication of the final regulations announced by the U.S. Department of Education.

variations and narrowing of eligibility criteria, increasing focus on social-emotional influences on developmental outcomes, and increasing requirements for accountability, monitoring, compliance, and data reporting. These situations also contribute to the recruitment and retention of qualified personnel, and are tied to changes occurring in other parts of the early childhood field (e.g., child care, home visiting, preschool education). Unless these challenges are resolved, early intervention systems will continue to be subject to political and economic cycles, and continued necessary services may not be assured for the most vulnerable children and families.

The needs that drove the creation of Part C continue to exist. Infants are born with



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**Although infants and toddlers grow and develop at different rates, most follow a predictable path and walk, talk, and learn in predictable ways.**

disabilities such as deafness and prematurity that will affect their development. Infants are born into extreme poverty, or to mothers with drug or alcohol addiction, which over time will affect their health and mental health and development. Infants and toddlers are abused and neglected, and their families become involved with child welfare system. Families of infants and toddlers with special needs have multiple concerns and priorities, and their own resources to draw on. It is unlikely that a single agency can address all the health, developmental, community, and support needs of the child and the rest of the family. Families who seek services continue to face a fragmented system. Despite encouragement and mandates for interagency cooperation and coordination, it is rare to find a truly integrated system, especially as families connect with hospitals, their own home and family, community, child care, and preschool settings.

### Beginning the Reauthorization Conversation: Policy Challenges and Questions to Consider

**T**HE CURRENT CONDITION of Part C early intervention has been influenced by many factors.

Some of the challenges in Part C are best addressed through federal or state policy, and some are more amenable to implementation strategies such as quality improvement, changes in practice, personnel development, coordination and collaboration, partnerships, and the like. In the sections below, we outline some of the key challenges and pose questions intended to initiate conversation at the local,

state, and national levels about the upcoming reauthorization of Part C. Although the reauthorization is not expected to begin until at least 2012, it is important that discussions begin now so that input can be provided by all stakeholders and maximum time is available to settle on the crucial federal policy enhancements to Part C.

### *Early Identification and Eligibility for Part C*

With dismal federal and state fiscal situations, and as American Recovery and Reinvestment Act (ARRA; 2009) funds are completely expended, states are restricting eligibility as one way of addressing the challenge of funding the program. A recent survey of states' eligibility criteria indicated that of the 43 states that responded, 6 states made eligibility criteria more restrictive in the last 3 years and 7 states are planning to narrow eligibility in 2011 (IDEA Infant Toddler Coordinators Association, 2010b). The most restrictive state eligibility requires a child to demonstrate a 50% delay in one or more developmental areas to be considered eligible for Part C. This pattern of narrowing eligibility, although an understandable response for a state in fiscal crisis that wants to stay in the Part C program, raises serious concerns about young children clearly in need of services not having them available.

### *Questions to Consider: Early Identification and Eligibility*

Establishing eligibility criteria and mechanisms for recognizing children who might be eligible for Part C are requirements

in the federal legislation. Some of the reauthorization issues to consider include:

- Should Part C establish a national minimum criterion for child eligibility? If so, what should this be? If a minimum eligibility standard is set under Part C, is it possible to avoid the unintended consequence of creating a “ceiling” that will result in fewer children being eligible?
- What other strategies can be used to encourage states to keep eligible criteria broad enough to address the needs of all young children with disabilities and their families?
- What might incentivize states to expand eligibility criteria to include children who are at risk for developmental delays?
- What changes to Part C could increase developmental screening and referral across all child- and family-serving systems, including pediatric health care, child care, home visiting, child welfare, and others?

### **Evidence-Based Practice**

Current and emerging evidence-based practices—including routines-based transdisciplinary models, primary provider, coaching, mentoring, and consultation—are being integrated into early intervention programs throughout the country. These approaches focus on serving the parent and child together, coaching parents as they learn to enhance their child’s development, consulting with other professionals, and providing services outside clinical settings. A national consensus workgroup was convened in 2007 to outline a set of practices to guide early intervention services in natural environments (see box Agreed-Upon Practices for Providing Early Intervention Services in Natural Environments). These principles and practices have yet to be incorporated into early intervention policy, integrated into training and technical assistance, or used in a systematic way to improve quality in early intervention.

Many programs striving to implement evidence-based practices are challenged by existing statutory language related to discrete early intervention services and the requirements to specify frequency, duration, and intensity. In addition, many in the early intervention field believe that the statutory definition of natural environments as a “place” or “location” (without regard to what occurs in that setting) limits the implementation of what constitutes evidence-based practice.

### **Questions to Consider: Evidence-Based Practice**

Evidence-based practice is considered an essential component of high-quality services, and federal legislation may be able

## **AGREED-UPON PRACTICES FOR PROVIDING EARLY INTERVENTION SERVICES IN NATURAL ENVIRONMENTS**

1. Infants and toddlers learn best through everyday experiences and interactions with familiar people in familiar contexts.
2. All families, with the necessary supports and resources, can enhance their children’s learning and development.
3. The primary role of a service provider in early intervention is to work with and support family members and caregivers in children’s lives.
4. The early intervention process, from initial contacts through transition, must be dynamic and individualized to reflect the child’s and family members’ preferences, learning styles, and cultural beliefs.
5. IFSP outcomes must be functional and based on children’s and families’ needs and family-identified priorities.
6. The family’s priorities, needs, and interests are addressed most appropriately by a primary provider who represents and receives team and community support.
7. Interventions with young children and family members must be based on explicit principles, validated practices, best available research, and relevant laws and regulations

Source: Workgroup on Principles and Practices in Natural Environments (2007)

to strengthen available research and other evidence. Some of the questions to consider during reauthorization include the following:

- What changes should be made to the existing statutory language (related to services, frequency, intensity, method, and duration) to support evidence-based practice for young children and their families?
- In what ways can federal policy facilitate the use of evidence-based practice? How can we ensure that new federal policy in this area does not inadvertently restrict state and local decision making?
- How should the Agreed-Upon Practices be incorporated into statutory language (e.g., the Findings and Policy section of Part C), or are there other sections of the statute and at the state and local levels to incorporate the Key Principles into program guidelines, standards, and quality improvement and accountability measures?
- What statutory changes, to which legislation, are necessary to ensure continued and adequate investments in research on early intervention services?

### **Workforce Capacity and Personnel Development**

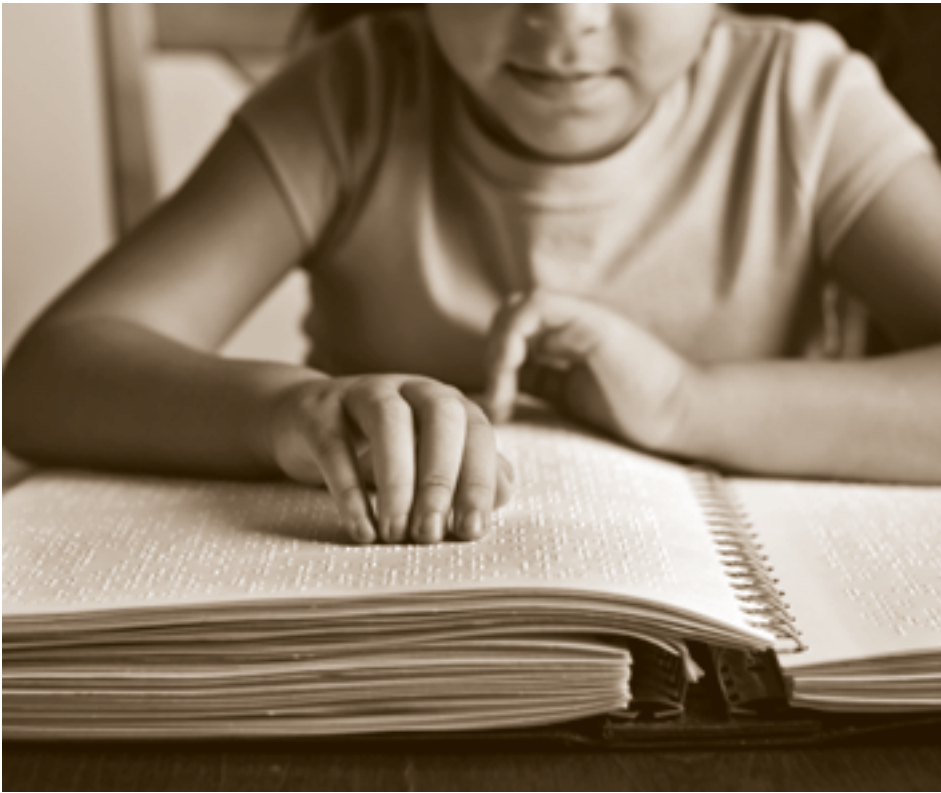
States report overall Part C personnel shortages, especially in rural areas, and ongoing capacity issues in meeting the needs of young children with disabilities and their families; vision service providers, bilingual staff, and infant mental health specialists are in especially short supply (Sopko, 2010). Across the early childhood field, there continues to be a tremendous need to prepare sufficient numbers of practitioners who are

adequately prepared to work with infants and toddlers, including those with delays or disabilities and their families.

Retaining qualified staff is also a problem. States report that early intervention salaries cannot compete with those offered by school districts, hospitals, and the private sector; inconsistent funding drives early intervention professionals to seek more stable work in other settings. The early intervention field is also quite varied, including at least 12 professional roles (e.g., early interventionist, nurse, social worker, speech therapist). States differ in their requirements for each role, in their partnerships with institutions of higher education, and in the extent that their professional development systems are integrated across sectors. States are called upon to build more comprehensive professional development systems, with a consensus definition of professional development that emphasizes acquisition of knowledge and application of this knowledge in practice. States should identify evidence-based practices, especially in promoting children’s social-emotional development, and base their professional development systems on these practices (National Professional Development Center on Inclusion, 2010). These challenges call both for increased investments in professional development at the pre-service and in-service levels and for research to document effective and promising professional development practices.

### **Questions to Consider: Workforce/Personnel Development**

- What changes in Part C language, IDEA Part D State Personnel Development



Councils required under the Head Start reauthorization in 2007 (Improving Head Start for School Readiness Act). However, these efforts do not always require inclusion of the Part C agency. For example, federal guidelines for Early Childhood Advisory Council membership require representation from either the Part C or the Section 619 preschool special education systems. In most states these systems are operated by completely separate agencies; having only either Part C or Section 619 preschool special education does not represent the birth-5 years continuum.

**Questions to Consider: Collaboration With the Broader Early Learning and Development Community**

Addressing the needs and concerns of families who have children with developmental disabilities requires coordination among multiple systems and functions. There may be changes to the Part C statute or other federal statutes that can facilitate collaboration between programs, funding streams, and system functions. Some of the questions to consider include:

- How can changes to IDEA or other statutes help ensure that state Early Childhood Advisory Councils have rich, full involvement of Part C and 619 to ensure the needs of all young children, including children with disabilities, are addressed?
- What statutory changes are necessary to ensure adequate and continued support for parent participation on state Part C Interagency Coordinating Councils?
- What can be done at the federal and state levels to encourage alignment of system functions such as Quality Rating Improvement Systems, measuring child outcomes, data collection/reporting systems, defining early learning guidelines, and professional standards?

**Accountability**

IDEA 2004 established a new accountability system requiring Part C state lead agencies to establish a multiyear State Performance Plan and submit an Annual Performance Report on 14 required indicators. These indicators relate to areas including increased child identification, the provision of timely evaluations and development of IFSPs, the provision of timely early intervention services, timely transition, and improved child and family outcomes.

Creation of state systems to meet these reporting requirements has resulted in significant costs in both human and fiscal terms. No additional federal funds have been made available to assist states in these efforts. In fact, with the exception of the much

**Early intervention enhances the capacity of families to promote the best possible developmental outcomes in their children.**

Grants, and additional investments are needed to improve state professional development systems?

- What partnerships at the federal, state, and local levels are necessary to build proficiency in social-emotional development among Part C providers and others who work with infants, toddlers, and families?

**Collaboration With the Broader Early Learning and Development Community**

**P**ART C EARLY intervention serves vulnerable children and their families. These children and families live in communities and will also be served by child care, home visiting, community-based early childhood programs, health, mental health, and family support programs. Simply put, children with special needs (whether they are identified that way or not) are going to be present in every child- and family-serving program. Policymakers as well as program administrators may see early intervention as separate from the early childhood education system, when in fact they should be viewed as integrally related. Therefore, early intervention needs to be integrated into every system that comes into contact with children or with pregnant or parenting families. At a minimum, all health, mental health, family support, and early childhood

practitioners should understand how to make a Part C referral if they suspect a child may have a developmental delay or if a parent has a concern regarding a child's development. A comprehensive system of early learning, health, mental health, and family support will go beyond the minimum and will be actively working to coordinate all aspects of the system. New federal policy initiatives such as early childhood home visiting and community mental health services for pregnant and parenting families also must integrate state Part C early intervention into the planning, evaluation, and service continuum.

Some states actively involve the Part C lead agency in creating comprehensive early childhood systems, coming together to coordinate professional development, mentoring systems, combined child and family service plans, integrated data systems, and community screening and outreach. However, much more can be done to make sure that infants and toddlers with disabilities and their families have opportunities to benefit from child care, home visiting, Early Head Start, and pre-K early learning efforts.

Efforts to create comprehensive state early development and learning systems have been under way through such efforts as the Early Childhood Comprehensive Systems state grants, the Build Initiative, and the Early Childhood Advisory



appreciated one-time ARRA (2009) funds to Part C, federal contributions to Part C have decreased in the last several years. In addition, changes in the measurement directions for these indicators as the process was initially implemented resulted in additional costs and data burden at the state and local levels.

In accordance with the new accountability requirements, states are now being monitored for compliance on the performance indicators. The processes for determining compliance, and verification that a state has corrected its areas of noncompliance, are also of concern to states. Federal directives have established a 100% compliance standard and a requirement that states must issue findings and ensure correction even when a single instance of noncompliance is identified (e.g., one IFSP meeting occurs 1 day late). Although it is important to ensure that all federal requirements are met and all children and families have available what Part C requires, it is equally important that accountability efforts do not compete with or interfere with the provision of quality services.

It is increasingly difficult for states to respond to changes in federal data collection and reporting. States have invested in electronic data systems to ensure timely and accurate reporting of required federal data. Any additions or changes to federal data requirements necessitate costly and time-consuming changes to states' electronic data systems. This includes the funding, expertise, and time for the design, development, training, and testing necessary to respond to new or revised federal data requirements. Continual modifications to the data collection requirements divert scarce resources, both fiscal and human, from services to administrative functions. Over time, this diversion has jeopardized achieving the overall purpose of the State Performance Plan and Annual Performance Report process—to improve results for children and their families.

Accountability is essential to ensuring quality services for children and families. However, the accountability process should be designed so it does not disproportionately demand resources and attention of state and local participants to the detriment of the provision of quality services.

### **Questions to Consider: Accountability**

Monitoring and other accountability measures can contribute to a high-quality service delivery system, yet an imbalance between compliance and outcomes can put stress on state systems. Some of the issues that could be considered in preparing for reauthorization include the following:

- What changes can be made to IDEA to create an appropriate balance between



PHOTO: ©STOCKPHOTO.COM/JO UNRUH

### **Early intervention salaries cannot compete with those offered by school districts, hospitals, and the private sector.**

addressing compliance, accountability, and ensuring successful outcomes for children and families?

- What are the appropriate indicators that will ensure an accountability system that addresses the purposes and mission of Part C?

### **Financing Systems**

Adequate and sustainable funding must be available to support the identification of all eligible children and to offer families the early intervention services and supports they need. Part C requires states to identify and coordinate all available resources for early intervention services, including federal, state, local, and private sources. On average, states use 9 different funds sources with a range from 1 to 23 sources (IDEA Infant Toddler Coordinators Association, 2010a). For example, from federal sources, states report using Medicaid (including Early Periodic Screening, Diagnosis, and Treatment), State Children's Health Insurance Program, Title V Maternal and Child Health, Champus/Tricare, Early Head Start, Temporary Assistance for Needy Families, Family Preservation, and Child Care Development Block Grant funds. However, although these sources pay for some services, the funding to establish the basic structure for identifying, assessing, and referring children—as well as assisting their families in determining how the services will be paid for—must come from Part C federal funds or state funds provided for these purposes. Moreover, as discussed below, actually paying for services, or being credited for those paid for with parent fees, adds to the strain on state finances.

In most states, funding is a perennial issue, never more so than in the current tight fiscal environment. Contributing to the immediate crisis is the lack of sufficient federal investment in Part C. The current Part C allocation of \$439.1 million is \$4.9 million lower than its highest funding level of \$444 million in Federal Fiscal Year 2004. Overall, federal Part C funds contribute about 12% of states' entire early intervention budgets (IDEA Infant Toddler Coordinators Association, 2010b). Despite the continuing lack of adequate federal investment in Part C, 2010 data from 40 states indicate that more than \$3 billion is spent on early intervention in those states. The one-time only investment of \$500 million in ARRA (2009) funds was an enormously positive contribution to states' Part C systems. Unfortunately these funds will be completely spent by September 30, 2011.

While funding has stalled, the number of children served under Part C continues to rise each year, from 284,170 children in 2004 to 348,604 on a one-day child count in 2009 (SPP/ARR Calendar, 2009). The one-day child count has serious flaws for determining the actual number of children served under Part C. Generally, most states who are able to report a cumulative annual count report serving at least twice the number of children over the course of a year as are reported on a one-day count.

State fiscal challenges have continued to impact Part C. According to a recent survey of the 43 states that responded to a question related to state funding, only 9 states reported a funding increase, 14 states had state funding decreases, and 20 states had state funding remain the same (IDEA

Infant Toddler Coordinators Association, 2010b). States are using different strategies to deal with the increasing fiscal challenges. As discussed earlier, some states have narrowed their eligibility criteria or eliminated at risk populations (infants and toddlers with multiple, significant risks such as prematurity, low birth weight, mothers with depression or a history of abuse or neglect, and so on, but who do not currently demonstrate a delay in development). For many of these children, early identification and intervention could prevent mild to moderate delays from deepening and becoming more challenging—and expensive—to address later on.

Other strategies include increasing family fees for services. Of the 39 states responding to a national survey question on changes in family fees, 10 states have not changed their fee structure in the last 3 years and plan no changes while 5 states increased family fees in that time and 3 states implemented family fees for the first time. One state will increase family fees in 2011. Some states are also decreasing provider rates to address fiscal challenges. Of 41 states responding to a question about provider rate changes, 10 states decreased provider reimbursement rates and 2 more states will decrease rates in the next 12 months.

An increasingly serious challenge for most state Part C systems is meeting the payor of last resort or maintenance of effort requirements. Part C is designated under federal statute as “payor of last resort” requiring states to exhaust all other federal, state, and local payment sources before using the Part C funds for services. A state must sign an annual assurance that the state’s budget for the upcoming year includes at least as much in state and local public funds as they spent in the year for which they most recently have data.

While in principle this requirement is designed to ensure all available federal, state, local, and private resources are used for early intervention, in reality it presents a major challenge in states by not allowing states to count revenue such as insurance proceeds and family fees in the definition of the “effort.”

The question must be asked: Why are federal requirements driving state fiscal decisions while states are paying the lion’s share of the cost of this program?

### Questions to Consider: Financing

Paying for early intervention services and the Part C infrastructure is a shared responsibility between the federal government and participating states. Some financing issues might be able to be addressed in the upcoming reauthorization; consider the following questions:

- Should the Part C allocation formula, currently based on state census, be revised? If yes, on what criteria should Part C be allocated to states? Should the new funding formula provide incentives for such things as increase in the number of children served or improved performance in other indicators?
- What level of federal investment is needed to collect, analyze, and use finance data such as:
  - The long term costs of not providing services to all children who need services;
  - Cost-benefit of successful interventions; and
  - Successful state financing models?
- How can states develop systems to demonstrate cost-effectiveness of early intervention?
- What changes need to be made in the payor of last resort language? For example, should the language include a state waiver opportunity as is available under Part B?
- What changes are needed in the Part C statute to allow states to use all available mechanisms to secure adequate and sustainable funding for early intervention?

### What You Can Do to Improve Part C Early Intervention

THE QUESTIONS POSED in this article, and the strategies that are ultimately selected to address them, will affect what happens at every level of early intervention. Most of the issues do not have easy answers. Making Part C more effective and more consistent with accepted practices will require thoughtful consideration of the range of solutions, and the pros and cons of each, by a diversity of stakeholders. Individual practitioners, parents, funders, community leaders, policymakers, and advocates can be, must be, actively involved in this process, and the resulting policies will be much more likely to improve early intervention. When the reauthorization of Part C begins in 2012, efforts will intensify and focus on federal policy. However,

you can start your advocacy efforts right now. Here are some ways you can become involved in improving Part C policies:

- Gather early intervention success stories; enlist the help of families in telling their own stories to elected officials and to business and civic leaders.
- Get to know elected officials. Talk to them about what you do in early intervention and why it is important to continue.
- Engage families in policy and advocacy work—invite them to join advisory councils, boards, and committees. Ask if you can participate in parent advisory groups, and share updates and concerns with each other.
- Know the “Agreed-Upon Practices” that guide early intervention; create ways to align your work with these principles.
- Start a conversation about improving early intervention—get together with your colleagues and discuss the questions posed in this article. Share your thoughts with state and federal Part C leaders.
- Become involved in state-level early childhood systems work. Learn about and get connected with your state Early Childhood Advisory Council.
- Build collaborations and partnerships at the local level. Visit other programs, and invite them in to see what happens in your own organization. Identify similarities in practices and requirements and aim for increasing coordination among programs.
- Be active in your professional organization and become familiar with their policy recommendations. Join others in advocacy networks, including the ZERO TO THREE Policy Network and the Council for Exceptional Children Division for Early Childhood.

### Conclusion

TO A LARGE extent, the initial intent of Part C has been accomplished. However, without addressing the fundamental unresolved issues in Part C early intervention, the potential will not be realized. Part C is an important building block for enhancing early development and must be fully recognized as a valued component of a comprehensive early childhood system. In the 25 years since the passage of Part C, a strong foundation for early identification, intervention, and family support has been laid, but renovations are now in order. Renovations in federal as well as state policy could improve quality, strengthen systems, and create a qualified and sufficient workforce to provide services. There must be adequate and sustainable funding to identify all eligi-

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ble children and to provide their families with the early intervention services and supports they need. Finally, federal policy initiatives such as maternal, infant, and early childhood home visiting and community mental health services for pregnant and parenting families must integrate state Part C early intervention into the planning, evaluation, and service continuum.

Improving and continuing to strengthen Part C early intervention will enhance state and local systems to ensure the needs of infants, toddlers, and families in the system can be addressed. This article presented some of the key challenges facing state systems; additional, and more detailed, strategic conversations will be needed. Beginning the conversation through the questions posed in this article is a good way to approach decisions and recommendations regarding possible changes to IDEA Part C. §

**PATRICIA A. COLE, MA**, is director of government relations at the ZERO TO THREE Policy Center. She leads the organization's work on federal policy in a wide range of issues important to infants and toddlers. She has more than 30 years of policy experience, having developed a particular focus on early childhood issues as a staff member with the Senate Subcommittee on Children, Family, Drugs, and Alcoholism and later as a consultant on children and family policy.

**CINDY OSER, MS**, is senior policy analyst, ZERO TO THREE Policy Center. Ms. Oser has more than 30 years of experience in pediatric nursing, public health, disability services, early childhood systems, and infant-toddler policy issues. She has been with ZERO TO THREE since 1998 in a variety of roles including founder and first director of the Western Office in Los Angeles, director of State Policy Initiatives, and technical assistance specialist with the National Early Childhood Technical Assistance

System. Prior to joining the organization, she served as chief of the Bureau of Early Intervention Services at the Ohio Department of Health and was loaned to Governor George Voinovich as part of the Ohio Family and Children First Initiative. Ms. Oser served as the first president and founding board member of the IDEA Infant Toddler Coordinators Association and currently serves on the national board of the Division for Early Childhood, Council for Exceptional Children.

**SHARON WALSH, MA**, is the governmental relations consultant for the Division for Early Childhood of the Council for Exceptional Children and the IDEA Infant Toddler Coordinators Association (ITCA). She also serves as a Part C consultant on the federally funded Data Accountability Center (DAC) and provides technical assistance to states in the implementation of the early childhood provisions of IDEA. She received her master's in speech pathology from George Washington University.

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# Building Relationships, Community, and Results Through the Early Childhood Assessment Workshop

HILLEL GOELMAN  
*The University of British Columbia*

The Early Childhood Assessment Workshop (ECAW) is a continuing effort by multidisciplinary professionals, academics, clinicians, parents, and researchers in the Canadian province of British Columbia (BC) to better understand the commonalities and differences in the theory and practice of early childhood assessment. Just as a good assessment of a child's developmental status must take into account the child's history and the context of the child's life, a description of the goals and accomplishments of the ECAW begins with the background and history of this gathering and, in particular, those factors that contributed to the high level of collaboration among the academic and community partners in the province of BC who conceived of, planned, implemented, and evaluated these six workshops.

The organizing committee for the ECAW included representatives from 8 different organizations (see box Members of the Early Childhood Assessment Workshop Organizing Committee).

The years leading up to the first ECAW were characterized by a high level of cooperation and collaboration among the academics and the professionals to produce high-quality, accessible professional development programs for the consultants working in the provincial Infant Development Program and Supported Child Development Program. The effort required close consultation to ensure that the courses would be relevant to the profession and would also meet required academic standards. From 1999 to 2003, a collaborative effort known as the University of British Columbia Child and Family Project (ChiFam) was funded by the Canadian

government to build (a) interdisciplinary linkages among different disciplines in the medical sciences, social sciences, arts, and humanities that dealt with children and childhood and (b) linkages between these academics and community-based professional organizations. ChiFam sponsored numerous seminars, workshops, classes, and a lecture series that was subsequently published as a book on interdisciplinary theory and practice (Goelman, Marshall, & Ross, 2004).

In 2002, the ChiFam group partnered with First Call, the provincewide child and youth advocacy collective, to produce a proposal for a longitudinal, collaborative set of studies on early child development. The successful proposal funded the Consortium for Health Intervention, Learning and Development (CHILD) Project, and each of the 10 studies was directed by a partnership that included an

academic research partner and a community-based professional. The participants worked to ensure that the research met required levels of rigor and also met clearly identified community needs. Taken together, then, by 2002, when the first discussions for an assessment workshop began, there was

## Abstract

The Early Childhood Assessment Workshop (ECAW) is a continuing effort by professionals, academics, clinicians, parents, and researchers in the Canadian province of British Columbia to ask questions about and to explore commonalities and differences in the theory and practice of early childhood assessment. The article describes the background, goals, and organizational principles and practices that brought together this multidisciplinary effort and summarizes the content and major foci over the 6 years of the ECAW. The author identifies several ways in which the ECAW has affected early childhood programs and services in British Columbia and how the information can provide support and guidance to other university–community collaborations in the area of early childhood interventions and programs.

## MEMBERS OF EARLY CHILDHOOD ASSESSMENT WORKSHOP ORGANIZING COMMITTEE

- The Early Childhood Educators of BC (ECEBC) is the professional organization of early childhood education (ECE) professionals in the province.
- The Infant Development Program of BC and the Aboriginal Infant Development Program are the major early intervention programs in the province, supporting children from birth to 3 years old who are at risk for developmental disability and their families.
- The Supported Child Development Program of BC and the Aboriginal Supported Child Development Program of BC provide supports to children from 3 to 12 years old with special needs both in center-based programs and in their homes.
- The Psychoeducational Research and Training Centre at the University of British Columbia supports the training of school psychologists in the use of psychoeducational assessment methods and instruments.
- The Human Early Learning Partnership is a university-based child development research center.
- The Consortium for Health Intervention, Learning and Development (CHILD) Project is a collaborative interdisciplinary research study within the Human Early Learning Partnership.

already a critical mass of academics and community professionals who had worked on a number of successful collaborative ventures, and these pre-existing activities were the solid foundation on which the ECAW was founded.

### Planning the ECAW: Rationale, Goals, and Implementation

THE INTEREST in the topic of assessment grew out of previous initiatives cited earlier. The university-based courses for Infant Development Program and Supported Child Development Program consultants dealt with different kinds of formal and informal approaches to assessing infants and young children. The seminars through ChiFam elicited much vigorous discussion around the purpose of early childhood assessment and the uses and misuses of different assessment techniques. The planning of the proposal for the CHILD Project resulted in the creation of three different studies, each of which focused on a different aspect of assessment. One

addressed the longitudinal study of children born with biological or environmental risk factors; the second attempted to create valid, reliable instruments for the identification of neuromotor disabilities (e.g., cerebral palsy) early in infancy; and the third piloted an approach to a universal program of surveillance of child health and development. The topic grew out of an organic process of discussion among the key players who, over many years, had built up a level of trust and collegial working relationships in these previous activities.

These discussions helped to identify the barriers that often prevented meaningful collaboration in the administration, interpretation, and implementation of assessment data. Both the community and academic partners recognized the philosophical and methodological variations among different kinds of assessment tools and procedures in early childhood. The discussions also identified service and communication gaps between different professionals, the long waiting lists for assessment services, and gaps or barriers between professionals and parents. There was also growing public awareness of and concern with assessment issues. There was controversy around the standardized measures used in elementary school settings and questions were being raised about a plan to institute the Early Development Instrument, a developmental checklist completed by all kindergarten teachers on all children in all kindergarten classrooms in the province.

The ongoing discussions among the various university and community partners acknowledged the widespread interest in and concern regarding the assessment of young children. Even before the specific notion of an “assessment workshop” was explicitly articulated, it was agreed that it was important to create a broad-based, inclusive setting in which:

- All questions can be asked and all concerns can be voiced;
- Research findings can be shared;
- Barriers between professions and academic disciplines are lowered;
- Barriers between the professionals and parents are lowered;
- Networking in local communities is facilitated; and
- The incredible range of assessment tools, procedures, and techniques in different disciplines and professions can be examined.

Each of the partners on the Organizing Committee represented an important sector of the world of early childhood practice in the province. The early intervention programs (Infant Development Program, Aboriginal Infant Development Program, Supported



PHOTO: ©ISTOCKPHOTO.COM/NICOLE S. YOUNG

**School readiness is probably one of the most debated and divisive topics in early childhood education and a topic of intense interest in British Columbia.**

Child Development Program, and Aboriginal Supported Child Development Program) represented organizations that focused on supporting children with special needs and their families. The membership of the Early Childhood Educators of BC (ECEBC) included early childhood professionals in both universal and targeted ECE programs for Aboriginal and non-Aboriginal children, as well as in multicultural programs in child care centers, preschools, and family child care homes. The ECEBC decided to mount this assessment workshop as a preconference on the day before the opening of the annual ECBC spring conference, which typically draws large numbers of participants from across the province and from a cross-section of early childhood groups and professions.

There were both many benefits and many challenges in the organization of the ECAW. The university-based academics initially took the lead in convening the Organizing Committee because of the staffing, infrastructure, space, and budget that various university sources (e.g., research funds, community outreach funds) made available. The university partners maintained a high level of mutual respect toward the knowledge, skills, and experience of the community partners. This mutual respect was based on, as noted earlier, previous shared initiatives and a strong sense of shared values, attitudes, and beliefs. As the group began to meet on a regular basis, the partners all played a role in suggesting both the content and format for the ECAW. The university partners took the lead in suggesting

appropriate academics whose areas of teaching and research would contribute to the ECAW. The commitment to collaboration resulted in a wide range of presentations that included work on quantitative and qualitative, formal and informal, diagnostic, screening, and observational approaches to early childhood assessment. Discussion, active listening, and consensus were the predominant modes of interaction on the Organizing Committee.

Perhaps the three biggest challenges faced by the Organizing Committee were time, money, and logistics. The time pressures were felt, first, because the ECEBC conference dates were set far in advance, and the clock was ticking for the next ECAW as soon as the previous year's ECAW had concluded. Second, all members of the Organizing Committee were (very) busy full-time employees of their host organizations or early childhood programs, which seriously narrowed the windows of opportunity to meet. As a result, the Committee typically met at 7:00 a.m. on weekday mornings so that they could discuss keynote speakers, presenters, the evaluations of the previous year's ECAW, and the ever-changing budget situation.

As in every initiative of this kind, there were real-life financial demands and constraints. Every effort was made to provide respectful honoraria to presenters and keynote speakers while ensuring that the registration fee for the event was affordable to all potential participants. The university donated the use of rooms and audiovisual equipment at no cost, and student volunteers helped to staff and direct traffic on the day of the ECAW. The partnering organizations drew up a memorandum of understanding, which stated that any deficits or profits from the ECAW would be shared equally by all participating organizations. Finally, to assist in the public relations, financial, and organizational demands on the ECAW, the Organizing Committee contracted with a private event-planning business that was also responsible for the ECEBC Annual Conference.

The success of the ECAW would be determined by the quality of the information shared at the workshop and the extent to which the workshop would give equal status and importance to all participants and differing perspectives.

## The Workshops

**T**HE FOLLOWING PARAGRAPHS provide a brief description of the six workshops.

### *The First Workshop (2003)*

The theme of the first workshop was "Understanding, Describing and Assessing Children's Development: A Workshop for Teachers, Parents and Significant Others in



PHOTO: © STOCKPHOTO.COM/ROSEMARIE GRANHART

**Over the 6 years of the Early Childhood Assessment Workshop, 40% of all presentations dealt exclusively with social-emotional development.**

Children's Lives." The keynote addressed many of the fundamental principles in assessment, and, in particular, that assessment should:

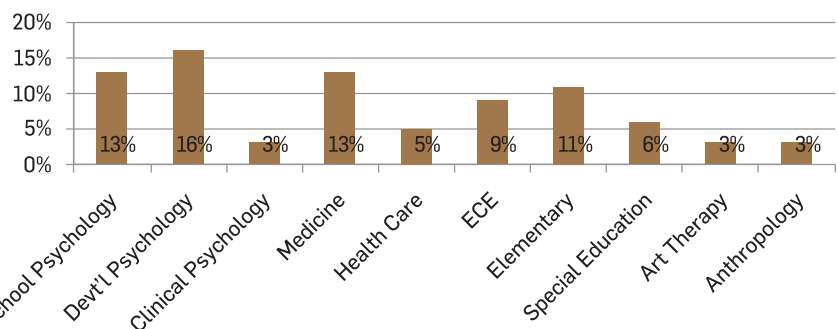
- Be child-friendly;
- Involve different domains of development;
- Involve parents closely in the process;
- Draw on a combination of formal, informal, and observational assessments in multiple settings; and
- Draw on specialists from different fields working as a team.

All six ECAWs involved professionals from different professions. Figure 1 reveals that psychology, medicine/health care, and education each accounted for approximately 20–30% of all presentations. Within each broad field, many specialties and subspecialties were

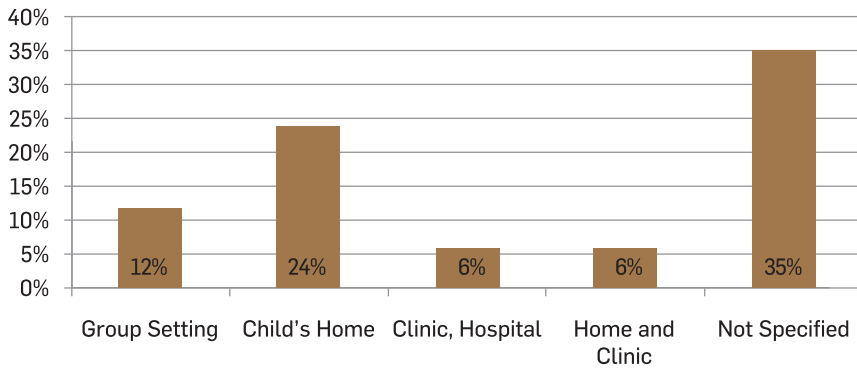
represented (e.g., pediatrics, neonatology, special education, ECE, occupational therapy, clinical and developmental psychology). For many of these presenters, the ECAW was one of the first times in their careers that they presented to an audience outside their own profession, and for many in the audience, the ECAW was a unique opportunity to listen to professionals whom they rarely, if ever, had the chance to hear.

Both informal and formal assessment methodologies were reported across all 6 years. The largest percentage of presentations (38%) described the use of child observations as its main methodology, 13% relied on a combination of observations and standardized tests, and only 5% relied exclusively on standardized tests. More than one third of all presentations (36%) did not report a specific methodology but discussed broader thematic issues (e.g., parent-assessor communication,

**Figure 1. Disciplines, Professions, and Presentations**



**Figure 2. Where Do Assessments Take Place?**



assessment in minority cultures) rather than specific methodologies.

### *The Second Workshop (2004)*

The theme of the second workshop was “Understanding the Challenges in Assessing Young Children.” The keynote addressed:

- The inclusion of families in the decision-making, planning, assessment, and service delivery components;
- The development of support and intervention services for the whole family, guided by the families’ priorities; and
- Giving families’ choices regarding their preferred level of participation.

Indeed, the trend of emphasis on child-versus family-focused assessment is also evident in ECAW presentations across all 6 years. Nearly 50% of all presentations focused on individual children and 30% dealt with family-centered practice issues such as parental consent, parental involvement, and parental interpretation of assessment data. Figure 2 suggests that these child-focused assessments were conducted in different locations: 32% of reported assessments were conducted in a group ECE setting; 24% in the child’s own home; 6% in a physician’s office, clinic, or hospital setting; and another 6% were conducted in both a home setting and an out-of-home setting. More than one third of the presentations (35%) did not specify a unique location because they dealt with broader thematic and not clinical or empirical issues.

### *The Third Workshop (2005)*

The theme of the third workshop was “Assessing ‘School Readiness’: What Does It Mean to Children, Parents and Educators?” School readiness is probably one of the most debated and divisive topics in ECE and a topic of intense interest in BC. The province had recently initiated a teacher-completed child development checklist (the Early

Development Instrument) on all kindergarten children in the province. Although not intended to be an individual diagnostic measure, the Early Development Instrument stimulated much discussion among parents and practitioners about the use and interpretation of developmental assessment measures in the early years.

The keynote addressed the ways of communicating the results of “readiness” assessments among professionals and parents. The theme of the ECAW and the keynote address elicited a number of seminar presentations at the workshop by academics, parents, and professionals on the topic of readiness assessment. For example:

- How Do I Feel About Going to School? The Role of Emotions in Children’s School Readiness;
- Reconceptualizing Readiness: Reflections on Encounters With Reggio Emilia;
- Physical Development and Motor Skills for School Readiness;
- “School Readiness”: Implications for Practice in the Kindergarten Year;
- “School Readiness”: Perspectives of Immigrant Families;

- Speech, Language and Hearing: Are You Ready?
- Aboriginal Perspectives on School Readiness; and
- Recognition of Developmental Risk: When to Watch and When to Act!

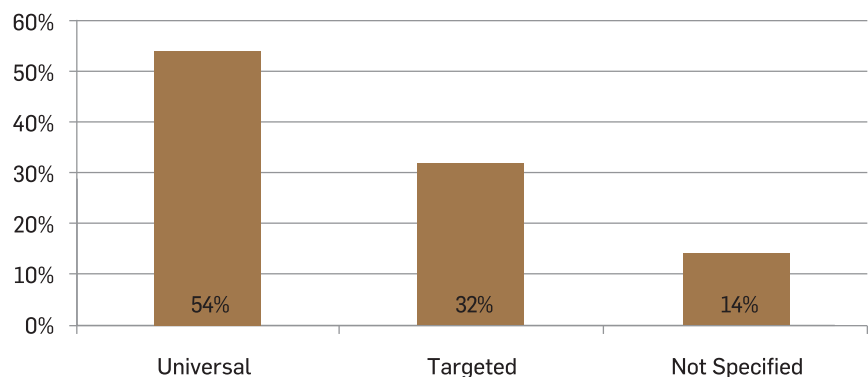
The readiness theme raised an important overarching set of questions about assessments of the developmental abilities of an entire population of young children and those that focus on specific, targeted populations of children. Figure 3 reveals the breakdown of universal and targeted approaches over the 6 years of the ECAW. More than half of the presentations (54%) dealt with topics that fit into the “universal” category of assessments, including, “The Early Development Instrument (EDI): A Tool for Mapping Children’s Readiness to Learn in British Columbia,” “The Child as Literacy Learner: How to Observe and Assess Children’s Developing Literacy Skills in the Preschool Years,” “Promoting School Readiness Through Community-Based Developmental Screening,” and “Surveillance and Screening, Partnerships and Advocacy: Integrated Services in Early Years.”

In contrast, 32% of the presentations dealt with targeted groups of children in specific categories of disability; for example, “Early Identification and Assessment of Children With Learning Disabilities,” “Steps to Building a Successful Transition Into Kindergarten for Children With Special Needs,” “Early Indicators of Autism in Young Children, Understanding the Social Cognitive Deficits in Children With Autism Spectrum Disorders,” and “Assessing Communication and Social/Emotional Development in Children Who Are Deaf and Hard of Hearing: Infancy to Early School Age.”

### *The Fourth Workshop (2006)*

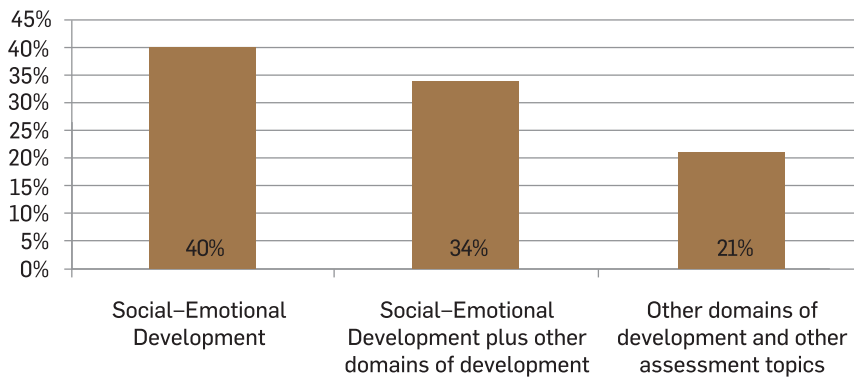
The theme of the fourth workshop was “Supporting Children’s Social and Emotional

**Figure 3. Focus of Presentations**





**Figure 4. Percentages of Domains of Development Covered in the ECAWs, 2003–2008**



Health: Assessment Tools, Research and Practice.” The keynote described an intervention program designed to enhance the social and emotional health of young children in group child care programs. This topic resonated very strongly with the participants of the ECAWs, as an analysis of ECAW keynotes and presentations over the 6 years focused on social-emotional development as well with other more traditional readiness skills such as cognitive, language, literacy, and numeracy development. As shown in Figure 4, 40% of all presentations dealt exclusively with social-emotional development and another 34% included social-emotional development in presentations on multiple dimensions of child development.

### *The Fifth Workshop (2007)*

The theme of the fifth workshop was “Innovative Assessment Practices: Supporting Families and Community.” One of the innovations explored was the possible implications and applications of psychobiological perspectives on early development and assessment. Participants were asked to consider the ways in which universal characteristics of communities and neighborhoods contribute to the ways in which individual characteristics of gene expression can predispose specific groups of children to respond positively or negatively to their social and demographic environments.

### *The Sixth Workshop (2008)*

The theme of the sixth workshop was “The Languages of Assessment.” The thrust of this ECAW was reflection on how parents, professionals, and researchers use their languages to conduct assessments, interpret, communicate, and act on a wide range of assessment practices. Again, the ECAW drew attention to a universal or population-health perspective as well as to an individual, targeted perspective.

Language is the medium needed to connect children with the professionals assessing them, to connect professionals from different disciplines, and to build meaningful, constructive relationships between professionals and parents. The words that are used in assessment practices have enormous power to affect both positive and negative changes for children and their families. The words can allow all participants in the assessment process to have meaningful conversations, dialogues as well as disagreements and arguments. With the use of words comes great power that must be used cautiously and carefully. Thus, language is woven deeply into the fabric of both population-based, universal assessments and targeted, diagnostic assessments.

### **Government Initiatives on Early Assessment**

The languages of assessment, as described in the sixth workshop, also refer to the language used by government in the public discourse on early childhood assessment procedures. Although it is impossible to draw a one-to-one correspondence between individual ECAW presentations and specific government policies, it is possible to argue that the ECAW created a climate that encouraged vigorous discussion, debate, and policy analysis during its first 6 years. Participants in the ECAW included representatives of different levels of government, school boards, advocacy organizations, training institutions, health and medical practitioners, and nonprofit organizations, all of whom carried the discussion on the importance and role of early childhood assessment far beyond the 1-day workshops. Thus, coincident with the emergence of the ECAW as a major forum on assessment, the government of the province of BC began to take a number of steps to expand assessment options in the province:

- In 2006, the provincial government announced programs for universal hearing screening for all newborns in the province and universal screening of hearing, vision, and dental health for all preschoolers in the province.
- In 2008, the provincial Ministry of Education, which had traditionally focused only on elementary education starting at kindergarten, consulted with many in the early childhood community and published an early learning framework on preschool education (British Columbia Ministry of Education, 2008). This report reflected the tone and much of the content of the discussions and presentations from the ECAWs. The report articulated a set of broad, “developmentally appropriate” learning goals, but instead of defining them as narrow “measurable outcomes,” the report raised a series of probing questions regarding each of the goals. These questions were designed to encourage the early childhood community to consider the wide range of possible approaches to understanding children’s knowledge, skills, attitudes, and developmental status. In this way, the report adopted a more descriptive child-centered approach rather than a prescriptive, curriculum-centred approach with recommended developmental milestones. The report itself, however, was considered a major milestone of development in the way in which the province began to look at early childhood in general and assessment in particular.
- The 2008 report (Goelman, Anderson, Mort, & Kershaw) came out strongly in favor of high-quality early childhood programs and recommended a pilot project to explore all educational, financial, and logistical aspects of providing publicly funded full-day kindergarten for 5-year-olds and half-day programs for 3- and 4-year olds. On the basis of this report, in 2008, the provincial government announced that it would create a new Early Childhood Learning Agency to study the expansion of public ECE programs to include full school-day kindergarten for 5-year-olds and pre-kindergarten for 4-year-olds by 2010 and for 3-year-olds by 2012. As part of this study, the provincial Ministry of Education commissioned the university partners on the Organizing Committee to conduct an extensive literature review on all aspects of early childhood program development, including the role of assessment.

The first 6 years of the ECAW have demonstrated that the languages of



**The words that are used in assessment practices have enormous power to affect both positive and negative changes for children and their families.**

assessment—words of power—were used to articulate practices and approaches that were shown to be effective for children and their families. The words of power were marshaled in public policy forums to prod government to introduce programs that could benefit an entire population of children, as well as targeted groups of children within that population. The challenge for future workshops is to build on the successes to date and to continue to be responsive to the needs and interests of the eclectic community that has increased every year. It is also important to continue building bridges across the parental, professional, disciplinary, and institutional boundaries that inhibit the much-needed integration and coordination that are needed to benefit children and families.

By giving equal weight to presenters with a wide range of experience and professional knowledge, the ECAW has succeeded in bridging assessment theory with assessment practice. Researchers have been able to articulate the practical applications of their theoretical work; clinicians and professionals have been able to discuss assessment issues that arise in their clinics and classrooms; and parents have been able to voice their questions and concerns about what assessment means in the lives of their children and families. This bridge between theory and practice is still under construction, but the researchers are confident that they have many of the tools to continue building this bridge and an informed,

committed community that will continue working on the bridge in the years to come.

## How to Plan a Successful Assessment Workshop

**T**HE TOOLS AND principles that have led to the successful ECAWs over the years can be used by other groups who may want to organize similar kinds of gatherings in their own communities. Here are the main lessons learned and recommendations for other communities that want to plan an assessment workshop of this kind.

1. Identify a working committee with representation from key stakeholders to explore interest in an assessment workshop. Representation should include but not be limited to:

- Early childhood professionals (e.g., educators, child care workers, early interventionists);
- Health and medical professionals (e.g., pediatricians; nurses; occupational, physical, and speech–language therapists; psychologists);
- Academics and researchers in these fields;
- Graduate students in these fields;
- Professional organizations;
- Parent organizations; and
- Government representatives.

2. Preliminary informal discussions leading to focus groups that focus on content questions such as:

- What are the main questions, needs, and concerns identified by their constituencies? More specifically, what do these different stakeholder groups see as the main issues regarding early childhood assessment?
- What are the current public policy, health policy, and education policy issues each profession is facing in terms of early intervention?
- What other (successful and unsuccessful) attempts have been made to address these needs?
- Are there any “stellar presenters” who should be considered (e.g., professionals and members of community agencies who are considered experts in a particular topic or champions for a specific cause)?

3. Preliminary discussions with the organizing committee members that focus on logistical questions such as:

- What kinds of formats work best for different audiences?

- What are the funding needs and constraints?
- What are the spatial needs and constraints?
- What are the timing needs and constraints?

4. What organizations or agencies want to become official members of the planning committee and sponsors of the assessment workshop? Are all member organizations willing to share in the costs of the workshop?

- A memorandum of understanding should be drafted and signed that clearly articulates the responsibilities of all member organizations. Different agencies bring different strengths and talents to the table, and the memorandum of agreement can reflect these differences as well as the shared commitments.
- A contract document may be developed with an agency providing logistic support for the event; one of the partner agencies may take this leading role and then share costs and expenses with the organizing committee.
- Clarity and transparency for each of the steps taken in this process are especially important with regard to the budget. Including the volunteer hours of committee members as in-kind work is important for tracking, especially for future grant applications when seeking funding to plan a similar event.

5. The organizing committee should select a target date that does not conflict with other major early childhood conferences or workshops. If possible, the date should piggyback on another event to maximize the potential attendance.

6. It would be a very good idea to identify a high-profile keynote speaker. Such speakers typically need to be booked far in advance. The keynote speaker will help draw attention to the workshop and can also help to identify the major theme for the workshop. High-profile speakers could be drawn from each community; they could represent academic, policy, or community advocates, and can also be drawn from the community of parents.

7. Delegates have appreciated opening and closing keynote panels with members who are meaningful representations of their geographical/professional/advocacy communities. Not only are these powerful speakers, but they also may not require a high financial investment in honoraria.

8. The committee should start the actual planning for the workshop 9 to 12 months

before the target date. The committee should select a timely and important topic that is of interest and concern to multiple professional, academic, and parent stakeholders. The planning committee should publicize a “save-the-date” campaign to give potential attendees a heads-up on the target date and also to request proposals for potential presenters for the workshop. The save-the-date campaign should be part of a year-long communications plan designed to remind potential attendees of the workshop. Although mailouts to electronic bulletin boards are preferred in terms of more people being reached and little or no costs, flyers posted strategically and faxed or mailed registration packages for small agencies with limited printing resources are also important.

9. The committee should consider all proposals for presentations and should also proactively seek out potential workshop presenters. Workshops should be selected if they are of interest; if the presenters are known to be good speakers; if the presentation fits into the theme of the overall assessment workshop; and if the presentation provides the assessment workshop with breadth, balance, and quality that incorporates cutting-edge research and recommendations for high-quality professional practices.

10. The program should be set approximately 5–6 months before the workshop. Registration materials should be sent to the memberships, staffs, and faculties of all participating organizations 4 months in advance and returned to the planning committee 3 months in advance. The final program content and logistical details (e.g., room assignments, photocopying and audiovisual needs) should be finalized 2 months before the target date.
11. The university partners and community partners should encourage their student members in their respective training and academic programs to serve as volunteers on the day of the workshop. They will help guide attendees to their room assignments and troubleshoot audiovisual and other concerns.
12. Feedback and evaluation forms should be provided to all attendees. These can be a combination of paper-and-pencil forms and Web-based and/or email feedback mechanisms. These are crucial in terms of learning what worked and did not work for the attendees.

All communities face specific and unique characteristics and these guidelines should be revised and adapted to those

local characteristics. The key factor in all aspects of planning is open and transparent communication among all parties and participants. ♪

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**HILLEL GOELMAN**, PhD, is a professor at the University of British Columbia in UBC's Department of Educational and Counselling Psychology, and Special Education and an associate member of the Department of Paediatrics and the School of Population and Public Health at UBC. He currently serves as chair of the Interdisciplinary Studies Graduate Program at UBC. His research centers on the short- and long-term effects of early childhood interventions on child development and he teaches graduate and undergraduate courses on early child development.

### Acknowledgments

The Early Childhood Assessment Workshop is a collaborative effort of academics and professionals. I thank the members of the Organizing Committee for their comments and feedback on earlier drafts of this article (in alphabetical order): Lorraine Aitken, Joyce Branscombe, Dana Brynelsen, Nicky Byres, Diana Elliott, Violet Jessen, Bill McKee, Mari Pighini, and Diana Tannahill.

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# Field Notes

*ZERO TO THREE Fellows share news and information about research, policy, and practice innovations in their work with infants, toddlers, and families.*

## THE PLAY PROJECT HOME CONSULTATION PROGRAM

Richard Solomon, MD, PLAY Project, Ann Arbor, Michigan

**T**HE PLAY PROJECT is an intensive, developmental, early intervention program for young children with autistic spectrum disorders. The cornerstone of the PLAY Project is a cost-effective home consultation program. Master's-level child development specialists coach parents to engage their child with autism. A home visit lasts 3 hours, and the time is roughly divided into thirds spent on modeling, coaching, and feedback. Visits are videotaped and, after the visit, parents are sent written recommendations directly related to video footage of the visit. The aim is to help children gain pragmatic language and social skills by promoting contingent, reciprocal, fun interactions. Consistent with the National Academy of Sciences (Lord, Bristol-Power, & Cafierol, 2001), parents are asked to provide 2 hours of engaging interactions throughout the day.

Through the PLAY Project's train-the-trainer model, more than 200 master's level professionals (e.g., MED, OTR, SLP, MSW) have been trained as PLAY Home Consultants (HC). Through licensed agencies in 27 states, thousands of children with autism each year are being served nationally. Trainees attend a 4-day intensive training

followed by 12-18 months of long-distance supervision during which trainees send videos to experienced supervisors for review. A training manual and fidelity measure guide HCs to provide a consistent, high-quality service. The total cost of training is \$4800-\$5800, depending on the number of trainees per agency. Successful completion of supervision results in certification.

Following publication of our pilot study (Solomon, Necheles, Ferch, & Bruckman, 2001), The PLAY Project was granted a Phase 1 Small Business Innovations Research National Institutes of Health grant to assess the feasibility of a multisite, randomized controlled trial. Our collaborators were Easter Seals National, which provided the sites, and Michigan State University, which provided independent evaluation. The Phase 1 trial showed feasibility and the PLAY Project received a \$1.8 million grant to implement a Phase 2 effectiveness trial. We are now in the second year of the 3-year study. In the first year we successfully recruited 60 children, from 3 to 5 years old, matched by age, gender, and severity, then randomized them into community standard services (special education preschool with school-based language and occupational

therapy services) or community standard plus PLAY Project Home Consultation. The trial follows the children for 1 year. A rigorous, pre/post evaluation design addresses whether (a) parents learn and implement the model, (b) children receiving PLAY Project consultation improved their functional, cognitive, and adaptive development when compared to control children, and (c) whether HCs show fidelity to the model. Altogether 120 children will be studied, making this one of the largest trials of its kind.

If the PLAY Project model proves to be effective, it will offer a replicable method of early intensive developmental intervention for young children with autism. The train-the-trainer model provides an efficient, low-cost system for quick dissemination to serve a growing, unmet, national need.

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## SUPPORTING CHILD SENSORY PROCESSING TO PROMOTE SOCIAL-EMOTIONAL INTERACTIONS

Frances A. Davis, MA, LPA, and Christina Ginter, OT/L, Family, Infant and Preschool Program, Morganton, North Carolina

**F**AMILY, INFANT AND Preschool Program Early Head Start (FIPP/EHS) intervention supports are specifically focused on effective strategies to strengthen and enhance caregivers' capacity to support child growth and development within natural learning contexts. The natural learning contexts found in everyday activities afford the identification of meaningful learning opportunities for caregivers to mediate child learning (Raab, 2005). This is true especially for promoting ongoing social-emotional competencies in children. FIPP/

EHS uses a model of promoting child social-emotional competencies called Between Us: Asset-Based Connections (Between Us: ABCs; Davis, 2010). Between Us: ABCs encourages caregivers' use of responsive caregiving and teaching strategies that increase child opportunities to experience and practice successful social-emotional interactions within natural learning contexts.

Patterns of sensory processing associated with a child's neurological sensory thresholds and self-regulation strategies

(Dunn, 2007) also play a prominent role in the development of social-emotional competency. Social interaction provides a mixture of tactile, auditory, and visual information, and caregiver responsiveness to child sensory thresholds and regulation strategies during social interaction can mediate successful child participation in social interactions.

Children with identified disabilities such as cerebral palsy, autistic spectrum disorder, and Down syndrome may be more vulnerable to sensory processing patterns that limit

their opportunities to participate and learn in everyday activities. These limitations can result in additional challenges developing successful social-emotional interactions (Dunn, 2007).

The core activities of Between Us: ABCs include the identification of child competencies and caregivers' use of responsive strategies that result in successful social-emotional interactions. Including a sensory processing assessment in Between Us: ABCs interventions promotes caregiver recognition of how the child's sensory thresholds and regulatory behaviors contribute to child success within the context of social-emotional interactions. The early interventionist, occupational therapist, or caregiver use this information in a practical approach to adapt or adjust the sensory environment and identify caregiver responsive strategies that will increase child participation

and promote new social-emotional competencies (Dunn, 2007).

For example, 3-year-old Samantha, diagnosed with autism, demonstrated a high sensory threshold for social stimulation by repeatedly running into or grabbing others. This resulted in intense emotional responses from peers and caregivers which encouraged her to repeat this behavior. Samantha also demonstrated passive regulatory competencies by withdrawing from caregiver and peer responses. Recognizing this pattern, caregivers chose quiet caregiver responses validating Samantha's attempts to engage her peers while providing a model of emotional regulation. Caregivers also increased daily opportunities for Samantha to meet her sensory needs through activities she enjoyed such as dancing and playing with cushions and pillows. Combining sensory processing supports with caregiver responsive strategies

prolonged Samantha's successful social interactions and promoted her independence in meeting her sensory needs through typical child activities.

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## FINDINGS FROM A MASSACHUSETTS STUDY ON DRUG-EXPOSED INFANTS AND EARLY INTERVENTION SERVICE USE

Taletha Derrington, MA, Boston University School of Public Health

**D**RIVEN BY EVIDENCE of both the direct and indirect detrimental effects of prenatal drug exposure, two separate pieces of federal legislation (Individuals With Disabilities Education Act, 2004; Keeping Children and Families Safe Act, 2003) now require states to ensure that drug-exposed infants are reported to child welfare and referred to Part C Early Intervention (EI). For EI, this is the first time two specific groups of children have been targeted for identification and referral, and it is an important opportunity to intervene when there is the most potential for a positive impact. Universal screening for drug use during pregnancy is impractical for many reasons, but data from vital statistics and hospitals provide an existing venue for risk identification. An algorithm was developed for this study to identify children who have been prenatally exposed to nonmedical use of controlled substances (that are potentially "illegal") using the Pregnancy to Early Life Longitudinal (PELL) Data System (Clements, Barfield, Kotelchuck, Lee, & Wilbur, 2006), with linkages between birth certificate and hospital-related service data (e.g., inpatient, outpatient, and emergency records of mothers and infants). In Massachusetts, this algorithm identified 7,350 drug-exposed infants born from 1998-2005 (1.2% of births).

PELL linkages to EI data indicated that 60% of these infants were referred at least once to a Massachusetts EI program before their 3rd birthday; 42% of referred children were referred multiple times. Preliminary analyses showed that referral rates differ by race/ethnicity, although these figures have not been adjusted for other potential predictors of referral. Asian/Pacific Islander children had lower odds of referral, and Hispanics had higher odds than Non-Hispanic White children. Although all of these children were identified through hospital and birth certificate data, preliminary data indicated that only 15% of referrals were made by hospitals. Non-Hispanic Black children had significantly lower odds of referral by hospitals than Non-Hispanic White children (unadjusted analyses, no differences for the other groups). Encouragingly, referrals increased significantly over time, with a noticeable increase occurring for children born after passage of the federal legislation.

Of the children who were referred, 88% received an evaluation. Of those, 90% were eligible, and 93% of eligible children enrolled in services. More than three quarters of enrolled children received services. Unadjusted odds ratios compared to Non-Hispanic White children indicated that Non-Hispanic Black children had lower

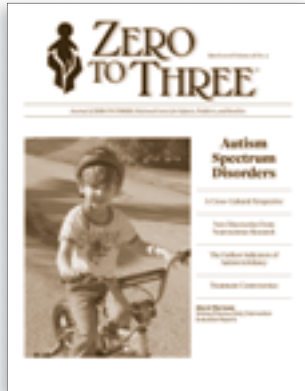
odds of evaluation, Hispanics had higher odds of eligibility, and children classified as American Indian/Other had lower odds of enrollment. Once enrolled, there were no differences by race/ethnicity in the odds of receiving services.

This ongoing study will identify and examine in more detail the individual- and program-level predictors of referral, enrollment, and retention, including the role of relationships and communication between EI providers within programs, and between EI programs and hospital referral staff, in program performance. Findings to date suggest the need for strengthened outreach from EI to increase referrals from hospitals. Racial/ethnic differences in various points of the service continuum require further investigation. §

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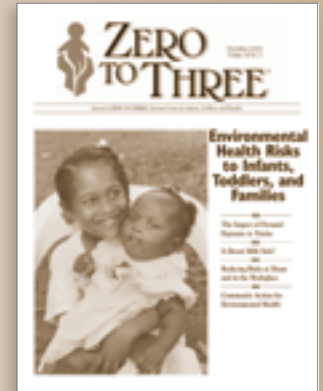
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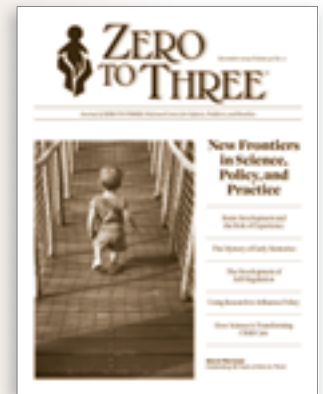
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# Jargon Buster

Given the multidisciplinary nature of our work with infants, toddlers, and families, we often come across words or acronyms that are new or unfamiliar to us. To enhance your reading experience of this issue of *Zero to Three*, we offer a glossary of selected technical words or terms used by the contributing authors in this issue. Please note that these definitions specifically address how these terms are used by the authors in their articles and are not intended to be formal or authoritative definitions.

Phrase	What it means
<b>Child Find</b>	Child find is a process for the early identification of children with disabilities and ensuring that children and families get needed services as early as possible in the child's life. The Individuals With Disabilities Education Act (2004) requires all states to have a comprehensive child find system to ensure that all children who are in need of early intervention or special education services are located, identified, and referred. (Find it in Brekken, page 32)
<b>Individualized Family Service Plan (IFSP)</b>	An IFSP is a plan for children ages birth to 3-years-old with special needs that identifies a child's current developmental level, what services will be provided to advance those skills, and family goals. An IFSP contains information about the child's strength, needs, likes, and dislikes and is driven by family needs, strengths, and goals. (Find it in Brekken, page 32)
<b>Inclusion</b>	The Division for Early Childhood (DEC) of the Council for Exceptional Children (CEC) and the National Association for the Education of Young Children released a joint position statement (DEC/NAEYC, 2009) which defines inclusion in part as "...the right of every infant and young child and his or her family, regardless of ability, to participate in a broad range of activities and contexts as full members of families, communities, and society.... The defining features of inclusion that can be used to identify high quality early childhood programs and services are access, participation, and supports" (p. 2). (Find it in Buysse, page 24).
<b>Part C Program</b>	Part C refers to the section of the federal Individuals With Disabilities Education Act (IDEA, 2004) that addresses services for infants and toddlers with disabilities. Part C provides grants to states "to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families" [Sec. 631(b)(1)]. Part C of IDEA remains an optional program for states, but if a state chooses to apply for Part C funds then the state must comply with all of the provisions of the law including identifying a lead agency and providing services to all eligible infants and toddlers and their families. (Find it in Hebbler, page 4)
<b>Universal Design/ Universal Design for Learning</b>	Universal Design is a concept that means supporting the access of children with disabilities to many different types of environments and settings through the removal of physical and structural barriers, whereas Universal Design for Learning reflects practices that provide multiple and varied formats to promote wider access to teaching and learning activities (DEC/NAEYC, 2009). (Find it in Buysse, page 24)
	DEC/NAEYC. (2009). <i>Early childhood inclusion: A joint position statement of the Division for Early Childhood (DEC) and the National Association for the Education of Young Children (NAEYC)</i> . Chapel Hill: The University of North Carolina, FPG Child Development Institute.
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